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Framework for Economic and Cost Evaluation for Continence Conditions

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Development of a Framework for Economic and Cost Evaluation for Continence Conditions

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Table of Contents

List of Figures

List of Tables

Acronyms

ABS	Australian Bureau of Statistics
ACAT	Aged Care Assessment Team
ADL	Activities of Daily Living
AHCPR	Agency for Health Care Policy and Research
AN-SNAP	Australian National Sub-Acute and Non-Acute Patient Classification
AR-DRG	Australian Refined Diagnosis Related Groups
ATSI	Aboriginal and Torres Strait Islander
CA	Cost Analysis
CBA	Cost Benefit Analysis
CEA	Cost Effectiveness Analysis
CISC	Clean Intermittent Self-Catheterisation
CNC	Clinical Nurse Consultant
CNS	Clinical Nurse Specialist
CRAGS	Community Rehabilitation and Geriatric Services
CUA	Cost-utility Analysis
DALY	Disability Adjusted Life Year
DBICI	Dowell-Bryant Incontinence Cost Index
DRG	Diagnosis-related groups
FIM	Functional Independence Measure
GEM	Geriatric Evaluation and Maintenance
GP	General Practitioner
HACC	Home and Community Care
ICD	International Classification of Diseases
ICS	International Continence Society
IQR	Inter-quartile Range
LOS	Length of Stay
MBS	Medical Benefits Schedule
MSSU	Mid-Stream Specimen of Urine
NATSEM	National Centre for Social and Economic Modelling
NCA	Nurse Continence Advisor
NSW	New South Wales
OAB-Q	Over Active Bladder Questionnaire
PADP	Program of Appliances for Disabled People
PCCL	Patient Clinical Complexity Level
PBS	Pharmaceutical Benefits Schedule
PFU	Pelvic Floor Unit
QALY	Quality Adjusted Life Year
RAP	Rehabilitation Appliances Program
RCI	Resident Classification Instrument
RDNS	Royal District Nursing Service
SD	Standard Deviation
SNAP	Sub-Acute and Non-Acute Patient
SPC	Suprapubic catheter
UDS	Universal Data System
UK	United Kingdom
US	United States
UTI	Urinary Tract Infection

Executive Summary

Overview of the Project Background and Methodology

As part of the National Continence Management Strategy, the Commonwealth Department of Health and Aged Care funded a project entitled: "Development of a Framework for the Economic and Cost Evaluation for Continence Conditions". It was also known as "Project 2", because a separate project entitled "The Development of a Suite of Outcome Measures for the Assessment of Continence Conditions" was undertaken at the same time, and was called "Project 1". The two projects were undertaken in parallel, because it was recognized that economic evaluation of the treatment of any given condition cannot be performed unless robust outcome measures are available to judge the effectiveness of that treatment, which then enables "cost effectiveness" to be measured.

The overall plan, developed by the National Continence Management Strategy, was that once the Outcome Measurement Suite had been finalised, the recommended outcome measures will be combined with the proposed Framework for Economic Evaluation, leading to a series of field studies, entitled "Project 3". In these field studies, the economic evaluation of a range of continence treatments will be undertaken. Hence the aim of the current Economic Project was to investigate methods that could be used to measure the cost effectiveness of continence management in the future field studies.

The current Economic Project was undertaken in two stages. The first stage (reported in the First Progress Report) summarised the literature review of previous observational and interventional studies regarding incontinence costs in the six client groups specified in the Commonwealth tender document (elderly, frail elderly, women of childbearing age, men and women at risk, people with dementia, and those with incontinence associated with neurological disease and injury). It also summarised the various methods available for economic analysis. The literature review revealed a striking lack of data or useful publications about the cost of incontinence. These findings led the project team to undertake seven pilot studies in the second stage of the project, to gather data about the cost of incontinence for the specified client groups in the acute care, chronic care and community settings. Full details of the findings and conclusions from these pilot studies are provided in the Second Progress Report. The purpose of these pilot studies was to determine the feasibility of various approaches to measuring the cost of incontinence, and incontinence management, in Australia.

During the planning phase of the Economic Project, a full day workshop was held with over 50 invited stakeholders, comprising nurse continence advisers (NCAs), physiotherapists, urogynaecologists, continence research nurses, geriatricians, rehabilitation physicians and health economists. The report of this meeting in Appendix J provides interesting material, ranging from debate about the definition of incontinence to be used in this study, discussion of the methodology for accurate data collection across a range of settings, and theoretical considerations regarding the "burden of care" of incontinence. This document was circulated widely and comments were incorporated into the construction of the seven pilot studies.

The final recommendations from the current project reported in the Third Progress Report drew on the literature review, the findings from the seven pilot costing studies, the report of Project 1 Continence Outcome Measurement Suite (which became available in final draft form in November 2003) and consultations with key stakeholders. A series of feasible and clinically important Field Studies are described. Other options for future studies are briefly outlined. A scoring system for prioritising these possible studies is described.

The Literature Review

Overall, review of the literature revealed a scarcity of economic analysis of incontinence and its associated costs. The most comprehensive reports by Hu (1986) are "top-down" estimated costs of the burden of incontinence in the American setting which dealt with younger cohorts and excluded intangible costs. Australian costing studies by Dowell et al. (1999) provided useful, validated instruments for collecting direct personal and medical costs of incontinence on a "bottom-up" basis.

There is clearly a dearth of Australian based studies focussed on the micro-costing of incontinence in specific settings and populations. As American costs are based on "billing", or prices charged to patients, such costs do not reflect the costs of resources used in caring for patients in the Australian health care system. There are differences in clinical practice. For example, ambulatory care in the United States is provided in private consulting rooms rather than hospital outpatient clinics, resulting in different overhead costs.

Economic evaluations that incorporate the assessment of intangible costs are very rare. Intangible costs include the value of pain and suffering and decreased quality of life. These costs cover mainly the costs of the impact of the condition rather than the cost of managing the condition. These costs are borne not only by the individual sufferer but also by those caring for them and more broadly by society. Assessments of intangible costs are particularly important in continence conditions because objective measures of the disease progression often correlate poorly with the effect of incontinence on the patients' lives. In particular, the perspective of who bears the costs should be from the patient and societal viewpoints. If Australia is to identify the "best buys" across the prevention-treatment spectrum, then valid economic studies are required that reflect the Australian health care system and associated funding arrangements.

The Pilot Costing Studies

Seven pilot costing studies were undertaken, as preliminary attempts to gather initial data about the cost of incontinence for the aforementioned target groups, who received different treatments in various settings. Two main costing approaches were taken: first, face to face "patient-level" recording of costs, and second, use of the current casemix classification systems for prospective or retrospective, analysis of presently available cost data. A one day survey of incontinence within the patients of a major teaching hospital was also undertaken.

The pilot study sites for the cost and utilisation data were selected according to criteria described in the original tender document of the National Continence Management Strategy. These criteria related to patient subgroups, treatment settings and types of cost data collection. As mentioned the patient subgroups considered were women of childbearing age, men and women at risk of developing incontinence, the elderly, the frail elderly, dementia patients and patients with incontinence associated with neurological conditions. The pilot studies did not include one of the largest incontinent groups in the community and in the hospital setting, those aged between 45-65 years. However, it is recognised that this group is a major user of resources and the identification of these patients' costs and resource use should form a major component of the proposed Field Trials.

The three treatment settings that were used for sampling purposes were acute care at St. George Hospital, and chronic care at Sutherland Hospital, Port Kembla Hospital, John Paul Village and Thomas Holt Memorial Village. Community care comprised of both Northern Sydney Area Health Service Aged Care Rehabilitation Unit, and ambulatory outpatients attending St. George Hospital.

In the Subacute or Chronic Care Setting (Sutherland Rehabilitation, John Paul or Thomas Hold Hostels) patient level costing (or "bottom-up" cost information) was collected. First, a daily log of staff hours and resource consumption was kept at the four sites. Patients were elderly, frail elderly, dementia patients and patients with incontinence associated with neurological conditions. The main findings were that the average daily costs of continence management alone varied from $42.85 per day for patients in the Subacute Rehabilitation setting, to $5.56 per day for patients living in a Nursing Hostel. Of the total 65 patients with valid data, 64 had episodes of isolated urinary incontinence, 25 had episodes of isolated faecal incontinence and 50 had episodes of combined urinary and faecal incontinence. The incidence of faecal incontinence was higher than expected. The work load of caring for incontinence extended almost equally across day, evening and night shifts, which was an unexpected finding.

Second, in the acute care setting at St. George Hospital, the management, care and follow-up of patients seen by a Nurse Continence Adviser (NCA) were documented. These were acute patients who were admitted for the treatment of conditions other than incontinence but were found to be incontinent, when consultation was requested with a NCA by the ward staff. Clinical data were recorded on White Index Cards routinely by the NCA. Average costs were assigned to these patients by timing a list of usual tasks associated with their care, thus providing unit costs per task then extrapolated across a series of 80 patients in four target groups. The main findings were that the average cost for nursing time and consumables per patient episode of care varied from $59.45 for patients with neurological disorders, to $39.63 per patient for women of childbearing age. The failure to assess patients age 40-65 was a major deficit of this study. No overhead costs of the inpatient stay were assessed, nor was the contribution from ordinary ward nursing staff measured. The simple costing method used in this "White Card" study (shadowing of NCA'S for three days by a research assistant, to produce a cost for their typical tasks, which was then extrapolated) produced useful data at a relatively cheap cost. These same 80 patients were further studied in a retrospective analysis of their casemix coding (see below).

Third, in the acute care setting at St. George Hospital, the average costs of managing incontinence in ambulatory outpatients at the Pelvic Floor Unit were estimated. The main findings were that over one

week, 92 occasions of service were costed, with a mean value of $37.97 per visit, but a standard deviation of $44.23 per visit. There is a 14 week waiting time for new appointments to the urogynaecology service, hence there is a large "unmet demand" for incontinence services in the outpatient setting. The method of costing was cheap, as the clinic clerical officer meticulously recorded the duration of all treatment visits and each clinician recorded their own consumables.

Finally, the Dowell-Bryant Incontinence Cost Index (DBICI), an instrument developed to measure the total costs of urinary incontinence (Dowell et al. 1999), was administered by Caroline Dowell, the Nurse Continence Consultant attached to the Northern Sydney Area Health Service Aged Care and Rehabilitation Unit, to community dwelling patients in the course of her community visits. The main findings were that direct costs to the patient varied enormously, from $36 per annum to $6,943.50 per annum. Since none of these patients had undergone any previous treatment, the figures represent the patients' economic "Burden of Disease" in caring for their incontinence. The sample size (n = 13) was smaller than desired (target n = 20) because some patients refused to divulge information about their incomes needed for the DBICI (this was an unexpected stumbling block that needs attention in future Field Trials).

Casemix analyses were undertaken in four parts. First, in the acute care setting, a computer-simulated modelling exercise was conducted to examine the effects of any urinary or faecal incontinence as well as urinary retention or faecal impaction upon a range of Diagnosis Related Groups (DRGs), using software in the St. George Hospital Department of Clinical Information. The main findings were that incontinence per se almost never affected the Cost Weighting for a range of DRG's, and only rarely did urinary retention or faecal impaction affect the Cost Weighting.

Second, a consecutive series of actual patients discharged over one month at this hospital, who had a secondary diagnosis of any incontinence, were studied (n = 36). When the DRG of incontinence was subtracted from their DRG, the Cost Weight did not decline.

Third, a simple counting of patients with a primary diagnosis of urinary or faecal incontinence over 12 months was done. The number of such patients (n = 57) did not appear realistic for a hospital with 46,000 separations per annum.

Fourth, the DRG coding of incontinence as a secondary diagnosis was examined by retrieving the medical records of patients referred to the Nurse Continence Advisors at St. George Hospital (in the White Card Study). The main findings were that in 57 per cent of these patients, the diagnosis of incontinence was not recorded by the clinical coders in the Casemix Department of the hospital. Because all patients seen in the wards by an NCA had a green sticker affixed to their clinical notes at each entry for care, there could be no doubt that Casemix Coding is not sensitive for the diagnosis of incontinence.

The overall conclusion of the four casemix studies was that DRG coding, in its present format, cannot be used for future economic analysis of the cost of incontinence in Australia.

A separate form of Casemix Analysis was undertaken in the chronic care setting. Information on the costs of bladder and bowel incontinence in sub-acute and non-acute patients was analysed retrospectively using the Australian National Sub-Acute and Non-Acute Patient (AN-SNAP) Classification. The original database was obtained by project personnel who had been involved in the original SNAP study. Data from 9,418 episodes of care in the sub-acute setting were analysed. The main findings were that analysis of inpatients was the most useful, because data for the subsets of ambulatory outpatients yielded sample sizes that were too small to reveal statistically significant differences. For inpatients in the Rehabilitation setting, 45 per cent suffered from bladder and bowel incontinence, 12 per cent had bowel incontinence alone, and 7 per cent had sole bladder incontinence.

The main findings were that whilst 82 per cent of inpatients with no bladder incontinence were discharged home after care, only 60 per cent of the incontinent were discharged home. The remainder went to a nursing home or further care facility. Conversely, only 4.6 per cent of those without bladder incontinence were sent to a nursing home, compared to 13 per cent of those with bladder incontinence. Similar results were seen for bowel incontinence (3.9 per cent versus 2.6 per cent).

The average daily care cost for those with incontinence of either type was significantly greater than those who were continent. Patients who began their episode of care incontinent but became continent were significantly cheaper to manage than those with persistent incontinence of either type. Confounding variables exerted an important effect upon all analyses. Major methodological flaws were noted in relation to the definition of incontinence because patients who needed bedpan assistance could be classified as bladder incontinent, and patients who needed help with constipation could be classified

as bowel incontinent on the FIM score. The lack of inclusion of medical costs within the analysis was a further major flaw.

It was concluded that the SNAP database system, in its present format, should not be used for economic analysis of urinary or faecal incontinence.

In the final substudy a census was performed at St. George Hospital on a single day by five members of the project team to determine the prevalence of urinary incontinence and the use of continence pads in acute admitted patients. The main findings were that 17.5 per cent of hospital inpatients admitted to leakage of urine, and of these 54 per cent used incontinence pads (i.e. 9.4 per cent of the total). These data further served to cast doubt on the accuracy of casemix coding data. These data also indicated that incontinent patients in the acute hospital represent a valuable opportunity for early detection of incontinence and early intervention, which has never been systematically explored.

Two difficult areas in the original tender could not be fully costed. Firstly, it proved difficult to obtain information about incontinence management from the Divisions of General Practice in our area. Therefore the cost issues from the Demonstration Model Projects, in Wangaratta, Hunter and Western Australia were considered. Secondly, the private nursing services proved to be problematic because they do not systematically record whether they visit a client for help with incontinence (as opposed to showering or dressing them because of arthritis etc.). They do not record whether any of their patients suffer from urinary and/or faecal incontinence. Hence only primitive data could be obtained about the use of Private Nursing Services for incontinence (refer Appendix G, p.168)

Summary of Costing Methodology

The value of the costing methodology was assessed according to the following criteria: precision of the cost estimate, resolution, timeliness, its ability to be generalised and data affordability. In general, data identified was of varying levels of precision, ranging from the least precise cost information provided by the AN-SNAP database to the very precise measures of the cost of incontinence offered by the use of the Dowell Bryant Incontinence Cost Index (DBICI). In terms of resolution, it was shown definitively that Diagnosis Related Group (DRG) codes were not of sufficiently fine resolution to capture data on costs for patients in hospital since 57 per cent seen by the Nurse Continence Adviser (NCA) were not given a DRG code indicating incontinence upon being discharged. It was also demonstrated that in the nursing home and hostel settings where DRG coding is not available, the daily collection of cost data using bedside log sheets was costly and labour intensive.

With regard to its ability to be generalised of the cost data, it was found that tremendous variations in costs of incontinence within each setting, for example, from $5.56 per day to $25.98 per day in the nursing homes and sub-acute settings. In the outpatient setting, an occasion of service ranged from $101.29 for a change of suprapubic catheter visit, to $19.90 for a medical follow-up visit. These differences may have arisen partly just because of the small sample sizes in the pilot studies. Hence any costing of care in these settings would require much larger samples to enable conclusions to be more widely applicable.

As regards the research costs of data collection, the "blue sheet" study in the sub-acute and residential care settings yielded the most precise measures of costs, but was the most expensive, requiring a team of seven project members to design, implement, assemble and analyse the data. The next most expensive was the retrospective analysis of SNAP data, but it yielded the least precise estimates of continence care costs because of the inaccuracy of the Functional Independence Measure (FIM) scores in defining continence status. The third most expensive study was the Nurse Continence Adviser (NCA) in the acute inpatient hospital setting, but this produced quite consistent data with good accuracy. The two cheapest methods were the study of staff and consumable costs in the outpatient setting and the DBICI/case history studies in community dwelling clients. These yielded the most highly variable data, but this was largely because of small sample sizes (n = 92, n = 13).

It appeared that there was a wide range in the magnitude of labour costs incurred in collecting data by different methods. Ideally, it would have been desirable to be able to examine the relative worth of the cost data in relation to the usefulness of the outcomes of treatment. This was not possible given the time frame of Project 2 in relation to the findings of the Outcomes Measurement Suite from Project 1, but will occur in Project 3 Field Trials. The budget planning for these studies will not only need to include the labour costs of gathering the economic data, but also the costs of collecting the outcome data, and appropriate statistical analysis.

Recommendations for a Framework for Economic and Cost Evaluation of Continence Conditions

In theThird Report, having assessed the value of the different costing methods, we then devised a matrix in which a range of costing methods can be used in conjunction with outcome measures developed in Project 1. These studies would yield *cost minimisation analyses* when two interventions have identical outcomes (outcome measurement is thus not required) and therefore one simply selects the cheapest. Studies which measure different outcomes of two interventions (such as frequency volume chart, pad test and quality of life measures allied to the same cost items) yield *cost effectiveness analyses. Cost utility analyses* evaluate different interventions using health preferences or utility measures such as willingness to pay or quality-adjusted life years.

By populating a matrix of this kind with studies from Australia and overseas, a number of different economic and cost evaluations are possible. Using the elements in this matrix (seeTable 41 of main text below) the capacity to frame an economic evaluation and develop a notion of what constitutes "best buys" for Australia can be progressively developed. Decisions can then be made regarding the relative investment in preventive and curative interventions.

Matrix Approach to Economic Evaluation of Continence Conditions

(See below table for Abbreviations key)

CONDITION STAGE	TARGET GROUP	SETTING	INTERVENTION	COST ITEMS	OUTCOMES SUITE	ECONOMIC ANALYSIS
At risk	1. Women after childbirth	Hospital OPD	Physiotherapy training	Personal and treatment costs (DBICI), costs of therapy	None measured	COI
	2. Women after childbirth	Hospital OPD	Physiotherapy training vs. simple education	Personal and treatment costs (DBICI), costs of therapy	Frequency volume chart, pad test, HRQoL	CEA
	3. Women after childbirth	Hospital OPD	Physiotherapy training vs. simple education	Personal and treatment costs (DBICI), costs of therapy	Health preferences, Utility, WTP, QALY, Frequency volume chart, pad test, HRQoL	CUA
	4. Men and Women post-operative	Hospital Wards	Strict catheter management/voiding protocol vs. routine care	IDC, SPC, Flip-flow valve, Ward bladder scanner, expert nurse, DRG based costs	Frequency volume chart, residual volume, HRQoL or QALY not applicable	CEA
Identification of early stage incontinence	5. Men with neurological condition, Alzheimer's, Parkinson's	Community	Early neurological treatment and optimal continence care vs. routine care	Personal and treatment costs (DBICI), costs for neurological treatment and bladder treatment	Frequency volume chart, residual volume, HRQoL, QALY	CEA/CUA
	6. Women postpartum or menopause	Community	Conservative therapy vs. simple leaflet	Personal and treatment costs (DBICI)	Frequency volume chart, pad test, HRQoL	CEA
	7. Women postpartum or menopause	Community	Conservative therapy vs. simple leaflet	Personal and treatment costs (DBICI)	Frequency volume chart, QALY, pad test	CUA
Acute care	8. Patients admitted for surgery to correct incontinence	Hospital	Comparison of different surgical procedures	Direct and indirect costs avoided, DRG based costs	None required	COI
	9. Patients admitted for surgery to correct incontinence	Hospital	Comparison of different surgical procedures	Direct and indirect costs avoided, DRG based costs	Frequency volume chart, pad test, HRQoL	CEA
	10. Patients admitted with another primary condition found to be incontinent	Hospital	See items above Row 4	See items above Row 4	See items above Row 4	See items above Row 4

CONDITION STAGE	TARGET GROUP	SETTING	INTERVENTION	COST ITEMS	OUTCOMES SUITE	ECONOMIC ANALYSIS
Acute care (continued)	11. Ambulatory patients – Men e.g. neurological condition, Alzheimer's, prostatic obstruction	Ambulatory	Early neurological treatment, early prostate treatment	Personal and treatment costs (DBICI), costs for neurological treatment and prostate treatment	Frequency volume chart, residual volume, HRQoL, QALY	CEA/CUA
	12. Ambulatory patients – Women postpartum or menopause	Ambulatory	Conservative therapy vs. simple leaflet	Personal and treatment costs (DBICI)	Frequency volume chart, pad test, HRQoL	CEA
	13. Ambulatory patients – Women postpartum or menopause	Ambulatory	Conservative therapy vs. simple leaflet	Personal and treatment costs (DBICI)	Frequency volume chart, pad test, HRQoL, QALY	CUA
Chronic care	14. Elderly, Frail elderly, Dementia, Neurological disease and spinal injury	Subacute	Timed voiding vs. random toileting	bedside cost records	Frequency volume chart, Nurse administered pad test, HR QoL or QALY by proxy	CEA
	15. Elderly, Frail elderly, Dementia, Neurological disease and spinal injury	Subacute	Disposable continence pad usage vs. linen change	Bedside cost records	Frequency volume chart, Nurse administered pad test, QALY by proxy	CEA
	16. Elderly, Frail elderly, Dementia, Neurological disease and spinal injury	Nursing home	Any of above non-surgical interventions vs. no intervention	Bedside cost records	Frequency volume chart, Nurse administered pad test, no HRQoL or QALY available	CEA
	17. Elderly	Community	Any of above non-surgical interventions vs. no intervention	Personal and treatment costs (DBICI)	Frequency volume chart, pad test, HRQoL	CEA
	18. Elderly	Community	Any of above non-surgical interventions vs. no intervention	Personal and treatment costs (DBICI)	Frequency volume chart, pad test, QALY	CUA

Conservative treatment = Pelvic floor muscle exercises, bladder training, anticholinesterase, oestrogen
COI = Cost of illness analysis
CEA = Cost effectiveness analysis
CUA = Cost utility analysis
DBICI = Dowell Bryant Incontinence Cost Index
HRQoL = Health Related Quality of Life
QALY = Quality-adjusted life year
WTP = Willingness to pay

In conclusion, a range of economic evaluation methods suitable for use in Australia, which would answer important questions about the "best buys" or optimal allocation of resources for incontinence management, have been identified. Outcome measures from Project 1 have been incorporated into a matrix covering the complete range of possible economic field trials. A scoring system has been developed for assessing the overall value of each field trial. A short-list of the most desirable field trials has been constructed by an urogynaecologist (K.H. Moore) and an economist (T. Ho). The short term (i.e. immediate) priorities were as follows:

1. *A randomized controlled study of bladder training (BT) versus anticholinergic therapy versus both, for urge incontinence*

   As discussed by the Teams, the Cochrane Incontinence Group is currently undertaking a pilot randomised controlled trial of this research question, to enable accurate power calculation yielding a rational sample size. The Cochrane group (based in Dunedin) will then seek funding for a multi-centre trial. We suggest that NCMS funding be devoted to this project, as it is one of the most important and poorly understood issues in the field of continence management. A subset analysis of the elderly (age >75 years) could be included within this project, which would address the issue of managing continence in the home dwelling elderly before they become so severely affected that nursing home admission is contemplated (usually associated with co-morbidities such as immobility, poor mental capacity, and recurrent falls).

2. *Markov Model for the Management of Incontinence in Australia*

   As regards a Markov Model for the management of incontinence, Ramsay undertook such a hypothetical analysis of the total costs of urinary incontinence treatments in the US, using a decision tree as dictated by the US AHCPR clinical practice guidelines in 1996. However many aspects of these AHCPR guidelines are now out of date, i.e. the management practices have changed since 1996. Nevertheless, the authors of the current Project are of the opinion that funding a study of incontinence treatment costs using a Markov Model based on current management guidelines (WHO) would be very informative (refer Section 16). New data about current management practices would be required to undertake this, however.

3. *Treatment/Prevention of Incontinence in Postpartum Women*

   Although Chiarelli has demonstrated (1999) high uptake of postpartum incontinence treatment and others have demonstrated efficacy of this regime (Morkved et al. 2003), no study to date has undertaken any economic analysis. Morkved et al. estimated that 6 antenatal women would need to be treated to prevent one case of postnatal incontinence. The cost of a conservative treatment programme by a physiotherapist, versus "usual care" (leaflets in the postnatal ward), has not been assessed. A risk scoring system could be developed to increase the yield of the treatment, e.g. rather than treating all postnatal women, those who are obese or constipated etc. could be considered. The study would require a long duration of follow up because spontaneous cure of postnatal leakage is known to occur. A Markov type analysis of this particular problem would also be useful.

   See Section 16.5 for the remaining proposed studies, for longer term consideration.

First Progress Report

Section 1. Introduction

As described in the original tender document RFT 55/0001, the purpose of this First Report is to "summarise the literature review of previous observational and interventional studies regarding incontinence costs in the six client groups. It will also summarise the literature review of the various methods available for economic analysis, and present arguments which have led the authors to select a favoured approach. It will indicate the format of pilot data collection that would be used to substantiate/validate the proposed economic framework for each client group".

This report begins by describing the literature search methodology and the way in which this literature was assessed. Next, the reported prevalence of continence conditions is discussed, because the varying definitions of incontinence have an impact upon the estimates of prevalence in the reviewed papers. The main body of the literature review outlines a conceptual framework for the analyses of costs and notes the difference between measuring the cost of incontinence and measuring the cost of incontinence management. The studies are then outlined in three categories: descriptive analyses (including cost of illness studies), comparative analyses (economic evaluation, including cost of care and cost comparison studies), and finally, review articles.

A major difficulty encountered during the literature review of comparative analyses was the lack of any consensus definition of "cure", "partial response" or "failed treatment". Therefore it is impossible to apply any "common yardstick" to gauge the success of treatments, and more importantly for Project Two, to gauge the economic value of different treatments. Clearly, Project One (The Development of a Suite of Outcome Measures) will need to provide such objective measures so that they can inform Project Three, the subsequent Field Trials.

This summary addresses issues concerning the applicability of these studies to the Australian context and drawing on the findings, outlines how an economic evaluation of continence conditions can best be approached in Australia. Specific areas of concern include:

1. The current status and gaps in data, information and knowledge
2. Issues of terminology and definition, and
3. Data requirements for the economic evaluation of continence conditions.

1.1 Methodology

1.1.1 Method of literature search

The bibliographic databases of published literature from journals, monographs and serials searched were MEDLINE, EMBASE, CINAHL, HEALTHSTAR, AMI, APAIS, and Ageline. The search strategies for MEDLINE and HEALTHSTAR used the terms "costs and cost analysis, economics, economic value of life, financial management together with faecal incontinence, urinary incontinence, and stress incontinence". A similar search strategy was used for EMBASE with fewer descriptors due to the lack of MESH words in this database. The search on APAIS, AMI and Ageline used only very basic terms such as "incontinence", "cost", "economic" and "finance".

All relevant references from the World Health Organisation monograph were retrieved and reviewed. Conference proceedings from the International Continence Society, the International Urogynaecology Association, the American Urological Association, the Continence Foundation of Australia and the Australian Urological Society were also included in the search. References were also obtained from unpublished work such as doctoral studies in progress.

A total of 939 references were obtained by the above search strategy. Two project meetings were convened to review the abstracts, retrieving only those papers which appeared to have cost information in them. From this, 85 full articles were retrieved and reviewed for inclusion in this report (see Appendix A for summary of each article). The remainder had made passing allusion to the cost of treatments but no data were actually collected in the study.

1.1.2 Method of assessment of publications

The literature selected was reviewed and categorised according to:

- *Incontinence type* including urinary (stress, urge, mixed) and faecal.
- *Client group* including elderly, frail elderly, men and women at risk, women of child bearing age, people with dementia, and those with incontinence associated with neurological disease or injury.
- *Treatment interventions* including behavioural, pharmacological, surgical, patient management with incontinence aids.
- *Care settings* including community-based practices, mainstream continence clinics, specialist health services (e.g. Aboriginal and Torres Strait Island services), residential aged care and supported accommodation, specialist medical practices and acute care.

An assessment was also made about the nature and value of each study according to the following categories:

- *Type of costing* including
  (a) No costing; where no costing of incontinence management or impact is identified in the study (despite the abstract indicating such data existed),
  (b) Cost of care: where the cost of care is measured without comparison,
  (c) Cost of illness: where the cost of management and the impact of incontinence are estimated for a given population without reference to outcomes,
  (d) Cost comparison: where the cost of two interventions are compared with or without outcome, impact or effectiveness measurement,
  (e) Review: provides a review of existing studies.
- *Outcome measurement* including assessment of impact, effectiveness or outcomes of an intervention regardless of the measure.
- *Value of the study* to the development of a framework for the economic and cost evaluation of incontinence conditions. Assessed as high, medium or low value.
- *Country* where the study was undertaken.

1.1.3 Overview of literature: common aspects

A table of the categorisation of the literature is provided at Appendix A. Several key observations emerge from the literature review:

- The literature focused heavily upon the costs of urinary incontinence, whereas faecal incontinence featured in only 8 per cent of publications reviewed.
- The population groups in the studies included women (50 per cent), the elderly (15 per cent), the frail elderly (12 per cent) and men (5 per cent – all post prostatectomy) with just one article each relating to spina bifida, multiple sclerosis, spinal injury and dementia. Only one study specifically dealt with younger women of childbearing age (Lam, 1992).
- Of the studies reporting specific interventions, there was a fairly even distribution of interventions across hospital and nursing home settings. A smaller proportion involved community based settings, largely relating to care in the home or community incontinence clinics.

Specific under-representation in the literature was noted in the following sub groups:

- Faecal incontinence, as mentioned, was very poorly represented
- Preventative interventions aimed at men or women "at risk" of developing incontinence
- Younger women of childbearing age.
- Specialist continence services for Aboriginal people or culturally diverse patients.
- Severely incontinent patients with multiple sclerosis/spina bifida/spinal injury.

It is particularly surprising that more attention has not been given to developing and costing strategies for early detection and prevention of incontinence in "at risk" groups, given it is widely accepted that incontinence is under-reported. The reasons for this are unclear and would warrant further consideration in the Australian context.

Although not focussed on prevention, Sampselle et al. (2000) evaluated the effectiveness of an evidence-based protocol aimed at increasing identification of women with incontinence in community clinic settings and improving their outcomes. The study provided evidence that a screening tool improved detection of incontinent women, from the usual 33 per cent voluntary request for help, to an incontinence

detection rate of 57 per cent in the women screened. A simple program of pelvic floor muscle and bladder training produced modest improvements in quality of life and lessened incontinent episodes.

Similar work undertaken by Gunthorpe et al. (2001) in Newcastle, Australia showed that basic continence therapy by general practitioners achieved a 74 per cent reduction in leakage on a 24-hour pad test. The latter study did not measure treatment costs or reduced costs of personal care items.

1.2 Urinary Incontinence: Definition and Reported Prevalence

Urinary incontinence is defined by the Standardisation Committee of the International Continence Society (ICS) as the involuntary loss of urine which is objectively demonstrable and is a social or hygienic problem (Abrams et al.1990). The ICS does not state whether this "problem" is one perceived by the patient, perceived by their relatives/household members/carers, or perceived by the health professional asking the question.

The fact that "incontinence" requires the urine leakage to be a social or hygienic "problem" opens up another semantic difficulty. One of the target groups for this project is "men and women at risk of developing incontinence". Therefore Project Two needs to consider the cost effectiveness of prevention strategies and/or early detection strategies. Herein lays the semantic difficulty. If a patient goes to their GP for a routine check-up and does not complain of incontinence, but has, for example, obesity, constipation and high parity that are all risk factors for stress incontinence, then the GP might introduce pelvic floor exercises as a prevention strategy. But if that same patient was given an incontinence screening questionnaire by the GP, and was found to leak some urine onto their undergarments once per week, then giving pelvic floor exercises to that woman would be an "early detection" strategy. The dilemma is that the first patient might well have had urinary leakage, but did not consider it to be a social or hygienic problem. The absolute demarcation between "incontinence" and "at risk for incontinence" is not yet clearly defined.

A review of 21 studies that reported the prevalence of urinary incontinence in large samples of adults reveals that much of the variation in prevalence is explained by differences in the reported frequency of incontinence and the gender and age of the subjects (Thom 1998, p. 477). This review indicated that incontinence was more prevalent in older people than younger people – it was twice as prevalent in older women as older men, and as five times more prevalent in younger women as younger men. Interestingly, a study of incontinence in elite nulliparous (no children) athletes reported that 28 per cent of women surveyed reported urine loss while participating in sport (Nygaard, 1994).

Table 1 Reported frequency of urinary incontinence by gender and age

	Ever Incontinent			Daily Incontinent		
Group	**Range %**	**Median %**	**Mean %**	**Range %**	**Median %**	**Mean %**
Older women	17-55	35	34	3-17	14	12
Older men	11-34	17	22	2-11	4	5
Younger women	12-42	28	25	Not available		
Younger men	3-5	4	5	Not available		

Source: Thom, 1998

A more detailed breakdown was recently provided by the UK Department of Health (2000, p. 7). The estimated prevalence of incontinence in different populations was as follows:

Table 2 Estimated prevalence of urinary incontinence in people living at home and institutions

	People Living at Home %	People Living in Institutions (both sexes) %
Nocturnal enuresis aged 7	14	
Nocturnal enuresis aged 9	9	
Nocturnal enuresis teenagers	2	
Women 15-44	5-8	

Women 45-64	8-14	
Women >64	10-20	
Men 15-64	3	
Men >64	7-10	
Residential homes		33
Both sexes in nursing homes		67
Wards for elderly and mentally infirm		50-67

Source: United Kingdom Department of Health, 2000

While the prevalence of incontinence decreases with age in young children and teenagers, it increases with age in adulthood and is significantly higher in the frail aged and infirm as reflected in the higher rates for patients under institutional care. It is understandable; therefore, that research effort in the area of urinary incontinence has focussed on women, the elderly and patients under institutional care.

Estimates of prevalence vary partly due to a lack of standardised definitions of incontinence. This lack of consistent terminology has a direct impact when surveys are carried out asking people whether they have bladder or bowel leakage problems. Herzog (1990) reported that asking a probing question following a negative response resulted in an additional 10 per cent of subjects reporting incontinence.

The collection of data regarding the prevalence and incidence of incontinence is central to any cost of illness study (defined in 2.1.1). Variations in the definition of incontinence can significantly alter the reported prevalence of incontinence and costs of treatment and care and thereby render inter-study comparisons invalid.

Thom (1998) noted that while the definition of stress, urge and mixed incontinence were not necessarily consistent across the studies reviewed, stress incontinence was the most uniformly defined.

Hu et al. (2000) and McGhan (2001, p.63) referred to a clinical condition called the "overactive bladder", characterised by chronic troubling increased frequency of micturition and urgency that may or may not include urge incontinence. Use of the term "overactive bladder" thus creates a problem, because sufferers may not actually be incontinent. Furthermore, the symptoms of frequency and urgency may arise from a host of other bladder conditions, such as interstitial cystitis, bacterial cystitis, and bladder cancer. Whilst the terms of reference of Project Two relate mainly to *incontinence*, studies that provide economic analysis of the overactive bladder have been included for the sake of completeness. A second reason for inclusion is that, left untreated, patients with an overactive bladder are certainly at risk for subsequent incontinence. Indeed, a key element of frequency and urgency of micturition is the *fear* of leakage, which compels the patient to rush to the toilet, thus disrupting their lifestyle and rendering certain types of occupation more difficult.

1.3 Definition and Prevalence of Anorectal and Faecal Incontinence

1.3.1 Definition

Anorectal incontinence is a broad term that includes both involuntary passage of flatus, as well as faecal incontinence. Within the symptom of faecal incontinence, leakage of only liquid stool may occur sporadically, in the presence of diarrhoea, which renders the patient more able to predict the problem and to take constipating medication. On the other hand, leakage of fully formed solid stool may occur without obvious warning, with total disruption of lifestyle.

A separate condition of incomplete rectal emptying also exists, leading to post-defecation soiling of the perineum and garments. Finally, faecal urgency may occur in patients with limited rectal capacity or altered anorectal sensation, such that faecal incontinence may occur if the toilet cannot be reached quickly enough (similar to urinary urgency).

1.3.2 Prevalence of Anorectal Incontinence

Faecal incontinence is defined as the involuntary loss of stool or flatus and is a distressing condition frequently seen by clinicians. It has previously been estimated that the prevalence of faecal incontinence

may be as high as 7 per cent (Talley et al. 1992) in the general community and up to 20 per cent of patients in elderly care institutions. However, because patients suffering from faecal incontinence may be reluctant to seek medical advice, the true prevalence is uncertain. In addition, there are very few large, methodologically sound studies examining the community prevalence of faecal incontinence. Most studies have focussed on those groups of individuals at high risk for incontinence such as the elderly, either in the community or in nursing homes. Other studies have used study designs, which might under- or over-estimate the prevalence, for example questioning one family member about all members in the household (Nelson et al. 1995).

However, by using a standardised questionnaire posted to 955 subjects randomly selected from a local Sydney electoral role of 68,821 voters, a St. George Hospital based study was able to determine the prevalence of faecal incontinence and to correlate this with possible risk factors (Lam et al. 1999). With a response rate of 71 per cent (M:F = 259:359), the overall prevalence of faecal incontinence, including incontinence to flatus, was 15 per cent and was surprisingly more prevalent in men (20 per cent) than women (11 per cent). There was also a significant association between faecal incontinence and a sensation of incomplete rectal evacuation, obstructed defecation, and subjective patient assessment of being constipated. In women there was a significant association between faecal incontinence and episiotomy, forceps delivery, perineal tears and hysterectomy.

It is clear that faecal incontinence is a common disorder in the Australian community and that these conditions are not confined to the elderly. Faecal incontinence is also associated with symptoms of constipation. Childbirth injuries and constipation are conditions that could both be avoided, and hence it should be possible to prevent incontinence in a significant proportion of people.

1.4 Brief Overview: Diagnostic Tests and Treatments Available for Urinary and Faecal Incontinence and their costs.

In order to understand the literature in this field, a brief summary of the subject is needed, although detailed texts are available regarding urogynaecology (Stanton and Monga 2000), urology (Walsh 1998) and colorectal surgery (Henry and Walsh, 1992).

1.4.1 Urinary Incontinence Diagnostic Tests and Treatments

At the time of conducting the literature search (in 2000) there were no rigorous longitudinal studies that described the natural history of urinary incontinence. The result of "no treatment" was not known i.e. whether spontaneous resolution of urinary incontinence occurs over time. This is important, because many comparative economic analyses would involve comparing the costs of an intervention with the costs of "doing nothing ". In other fields such as diabetes or ischaemic heart disease, one can assume that "doing nothing" results in a steady downward trend towards poor health, but this cannot be assured for urinary incontinence. Since the literature review, 2 longitudinal studies have been published, showing that there is some spontaneous resolution. (Moller et al. 2000 and Samuelson et al. 2000)

At the time of writing the first report, no data was available to indicate whether mild incontinence was definitely more amenable to a permanent "cure", compared to moderate or severe incontinence. Therefore the usefulness of an early intervention strategy had no scientific or economic underpinning at this time. Since this First Report was undertaken, one of the Project Team (KH Moore) published data to show that 65 per cent of patients with mild incontinence can be cured by conservative therapy (defined as dry on a pad test), compared with only 35 per cent of patient's with moderate incontinence (Moore et al. 2003). The costs of treating mild incontinence are substantially lower than treating moderate incontinence (O'Sullivan et al. 2003). Finally, no data is available to indicate whether prevention strategies are usefully applied to patients at risk of incontinence.

The main types of urinary incontinence are stress (leakage with cough), urge, mixed (i.e. both stress and urge), and overflow incontinence associated with outflow obstruction or an atonic bladder. Diagnosis requires appropriate history and physical examination, then a frequency volume chart (bladder diary) and urine microscopy with culture. Although these provide a provisional diagnosis upon which conservative therapy may be based, full diagnosis requires a test of bladder filling and emptying (cystometry with urine flow measure), that may be performed with imaging such as X-ray contrast dye (called video urodynamics) or by ultrasound. The severity of urine leakage is measured by a one-hour nurse-administered pad test, or by a 24-hour home pad test if the patient is able, or by a bedside bladder diary or "wet check" record in the nursing home.

The main treatments for urinary incontinence are as follows:

i. Stress incontinence in women

(a) Pelvic floor muscle strengthening exercises, performed solely by the patient, or under supervision of a nurse continence advisor or physiotherapist over 12 weeks.
(b) Electrical stimulation therapy to induce maximal muscle contractions over 12 weeks, usually requiring physiotherapy supervision.
(c) Intravaginal devices that support the urethra may be worn, not widely available.
(d) Surgical procedures range from the relatively non-invasive, such as Stamey needle suspension (very poor longevity), to the more invasive abdominal Colposuspension (very effective up to 5 years, some progressive fall off over 20 years). More recently, the laparoscopic approach to colposuspension has been developed, largely on the grounds of reduced hospital stay and early return to work, although longevity of success remains controversial. The Tension Free Tape has become the most commonly used procedure since the late 1990's worldwide. In specific cases, trans–urethral injections of collagen are effective. In severe or refractory cases, an abdominovaginal sling operation, or insertion of an artificial sphincter, may be used.

ii. Stress incontinence in men

In men, stress incontinence almost invariably results from open prostatectomy, often for prostatic cancer, in which the bladder neck region and its nerve supply are traumatised. Recent randomised trials showed that conservative therapy is little better than watchful waiting, as much spontaneous improvement occurs over 6-12 months. In refractory cases, injections of collagen, or insertion of artificial sphincters, are used.

iii. Urge Incontinence

(a) The primary treatment is bladder training, to prolong times between voids by ignoring urgency and by contracting the pelvic floor muscles to stop urine escaping.
(b) An important second treatment is anticholinergic drugs to inhibit the bladder muscle contractions, but side effects of dry mouth and constipation can distress patients, limiting the usefulness of such drugs.
(c) In non-responding females, cystoscopy to exclude malignancy is useful when cystodistension may be tried (to enhance bladder capacity) although longevity of benefit is poor. In non-responding males, exclusion of outflow obstruction e.g. prostatic hyperplasia is important: resection of prostate may improve/cure symptoms.
(d) In rare, severely refractory cases, the bladder may be enlarged by placing a strip of bowel across a "clam" shaped opening in the dome of the bladder, with an operative mortality of 1 per cent.
(e) In specific neurological cases, surgical implantation of a spinal cord neuromodulation device may be effective.

See Table 3 below for the Medicare Rebate items for these procedures.

iv. Overflow Incontinence

(a) In males with outflow obstruction, prostatic resection is usual.
(b) In females, the most common condition after surgery for stress incontinence (i.e. a relative outflow obstruction), treated by short term suprapubic catheter (SPC) or long term clean intermittent self catheterisation (CISC).
(c) In neurological patients, this is usually treated by CISC, but an indwelling SPC also used – this requires monthly catheter changes by a health professional. Indwelling urethral catheters with leg – bags are less well tolerated and also require changes.

Table 3 Prices of Tests and Treatments for Urinary Incontinence

Test/Treatment	Medicare Rebate (85% of scheduled fee)	Hospital length of stay (days)
Urine culture	$17.10	n.a.
Cystometry	$109.25	n.a.
Uroflowmetry	$18.25	n.a.
Videourodynamics	$283.45	n.a.
Pad Test	nil	n.a.
12 week physiotherapy	nil	n.a.
Stamey Suspension	$224.20	3-5

Colposuspension	$472.65	5-7
Collagen injection	$152.15 + $4000.00 collagen	1
Laparascopic Colposuspension	$501.50	1-2
Abdominovaginal sling	$472.65	5-7
Artificial urinary sphincter	$1064.45	
Anticholinergic drugs		n.a.
Cystoscopy	$110.25	1
Clam cystoplasty	$1246.20	7-10
Sacral neuromodulation	$692.60 +$7000.00 implant	5-10

Source: Commonwealth Department of Health and Aged Care Medicare Benefits Schedule Book (1st November 2000)

1.4.2 Faecal Incontinence Tests and Treatments

The main types of faecal incontinence arise from anal sphincter trauma, anal sphincter denervation, or both. Incomplete faecal emptying can arise from rectocele prolapse into the vagina. Complete rectal prolapse beyond the anus can also cause incontinence. Constipation with faecal impaction can cause overflow incontinence, particularly in the elderly. Diagnosis requires appropriate history, physical examination, and then tests are selected as to likely pathology but which may include ultrasound of anal sphincters, anorectal manometry, pudendal nerve function tests, defecating proctogram, or colonoscopy. Tests to measure severity are not available, although an overall score to grade severity and quality of life impact is in use (Wexner Scale; Vaizey et al. 1999).

The success of conservative physiotherapy is controversial. For leakage of liquid stool, constipating agents such as Imodium are effective (which also enhance anal sphincter tone). Surgery to reconstruct the anal sphincter is effective in isolated defects, but is best performed immediately after an obstetric injury (as yet, not common practice). Surgery to enhance the mechanics of defecation (post-anal repair) may be helpful. Vaginal repair is commonly effective for rectocele. In refractory cases, a transposition of the gracilis muscle from the thigh, to fashion a neo-sphincter, is done but the muscle must be stimulated for 12 weeks after surgery to enhance its resting tone. In end-stage incontinence, an artificial anal sphincter may be implanted. The Medicare rebate fee for these procedures is given in Table 4 below.

Table 4 Prices of Tests and Treatments for Anorectal Incontinence

Test/Treatment	Medicare Rebate	Hospital length of Stay (days)
Sphincter ultrasound	Not available	n.a.
Anorectal Manometry	$123.55	n.a.
Pudendal nerve tests	$165.30	n.a.
Defecating Proctogram	$111.65	n.a.
Colonoscopy	$73.70	n.a.
Course of Imodium	$120.00	n.a.
Anal Sphincter Repair	$443.20	3-5
Post-Anal Repair	$325.90	3-5
Delorme Op. for rectal prolapse	$370.60	3-6
Vaginal repair rectocele	$311.60	4-5
Graciloplasty with stimulation	$666.80	10-14
Artificial Anal Sphincter	$1064.45	n.a.

Source: Commonwealth Department of Health and Aged Care Medicare Benefits Schedule Book (1st November 2000)

Section 2. Introduction to Health Economics, Definition of Terms

2.1 Basic Concepts of Health Economics

The discipline of health economics deals with how scarce resources are used. This section on economic methods focuses on the principles and techniques used in economic evaluation to support decision making, when alternative uses of resources are being considered for health care delivery.

2.1.1 Economic Evaluation for Health Professionals

Health professionals are becoming increasingly involved in either carrying out economic evaluations or interpreting and applying findings from economic evaluations to their own clinical scenario. There are a number of reasons why this is so. As providers of health care, health professionals are inevitably closely entwined with the evaluation of any health care process, including the effects of any changes. In particular, in their role as advocates for their patients, health professionals provide valuable insights and understanding of the different aspects that need to be considered in patient care and what society in general expects from the allocation of resources to health care. This includes a consideration of equity of access especially to disadvantaged groups in society. They are also in the best position to provide advice on the efficacy and effectiveness of any interventions or programs. Because resources are scarce, yet there is an infinite demand for health care, planning services to satisfy each and every individual's wants is impossible. The needs of the society/community must also be considered. Thus the framework of health economics is to indicate the most cost effective use of scare resources.

The health professional is bound to make the best possible decision for his/her patient based on best available knowledge and evidence, and the available resources. Well accepted clinical practices such as triaging of patients in emergency departments and the compilation of waiting lists based on clinical need and urgency are based on the premise that there are limited resources and prioritisation is inevitable. Clinical decisions are tempered by awareness of resources and their distribution amongst those who need to share in these limited resources.

2.1.2 Different Perspectives in Economic Evaluation

The conceptual framework of economic evaluation differs according to the type of decisions in question, the intended purpose of the analysis, the practical measurement challenges and the perspective of the analyst. If the perspective adopted emphasizes the value that the individual places on outcomes, then the total value of the consequences including willingness-to-pay, patient utility not directly related to the health outcome (e.g. reassurance) and benefits accruing to the patient, family, health and other sectors would need to be accounted for. If the perspective of the analysis is that of allocation of the health sector budget, only health sector resources need be considered with the health improvements gained. Willingness-to-pay valuations are not used in this analysis since they reflect non-health attributes not funded from the health budget. If the perspective of the analysis is that of a broad societal view, costs include resources consumed in the health sector and other public and private agencies, and costs incurred by the patient and their families and employers. Benefits from the societal perspective encompass not only improvement in the patient's health state, but include costs savings across different government and non-government agencies or providers.

Because of the different forms which economic evaluations can take due to these varying perspectives and objectives, it is difficult to prescribe a single standard form of economic evaluation. The perspective from a single setting or institutional framework may be too restrictive in the context of making decisions on resource allocation within a constrained health budget. A broader societal perspective allows consideration by various providers and funding groups of the effects on resources across different settings.

2.2 Definition of Economic Terms

Economic evaluation is "the comparative analysis of alternative courses of action in terms of both their costs and consequences" (Drummond et al. 1997). Thus the tasks which characterise all economic evaluations are to identify, measure, value and compare the costs and consequences of the alternatives being considered.

The various methods of economic evaluations differ in the way they itemise and value the costs and the consequences. The choice of which economic evaluation to undertake depends on the aims and viewpoint of the decision-maker.

The following section describes in more detail each type of economic evaluation. These notes are provided as a guide in general outline to the concepts and definitions of economic analyses. Each section on the economic analysis will commence with a definition of the type of evaluation, its strengths and weaknesses, its application and an example.

2.2.1 Descriptive Cost of Illness studies

The literature refers to "cost of illness" study as a key method of economic analysis to value the economic impact of a disease. Hu described the economic burden of an illness as the "total value of all resources used or lost by society as a result of it" (1990, p. 592). Viewed in this way, the "cost of illness" is a more extensive and all encompassing concept than the cost of incontinence management.

In the literature, the economic impact of incontinence using the cost of illness approached can be considered under the following categories of costs: direct, indirect and intangible costs. According to Hu (1990) and others, these costs comprise:

- *Direct Costs* include routine personal care, such as purchase of protective pads by the patient, diagnostic costs, treatment costs, and consequences of care costs. Individuals, organisations and government incur these costs when trying to ameliorate the impact of incontinence on individuals and society.
- *Indirect Costs* include lost wages for patients and their caregivers, the cost of time spent by unpaid caregivers assisting in the management of the condition and lost productivity as a result of mortality. While these costs extend the range of costs to be considered in the management of incontinence, they also include costs related to the impact of incontinence (i.e. lost productivity and leisure time).
- *Intangible Costs* include the value of pain and suffering and decreased quality of life. These costs almost exclusively cover the costs of the impact of the condition rather than the cost of managing the condition. These costs are borne not only by the individual with the condition but also by those caring for them and more broadly by society.

2.2.2 Cost of Incontinence versus Cost of Incontinence Management

In reviewing the literature on continence conditions, it is important to draw a distinction between the cost of incontinence and the cost of incontinence management. The difference arises because the costs of incontinence management often exclude a significant proportion of indirect and intangible costs. The choice of which costs should be collected depends on the policy perspective of the study. If an approach is taken to valuing the economic burden of incontinence on society as a whole rather than simply on the cost of care + diagnosis + treatment, then the full range of costs as outlined above should ideally be included from a policy perspective. Few studies have succeeded in measuring in full indirect and intangible costs.

It is also important for methodological reasons to specify exactly which costs are being collected given the potential for unintended "double counting" in a cost of illness study. If, at an aggregate level, the cost of managing incontinence is combined with the costs of lost productivity and reduced quality of life, there is a risk of wrongly attributing and including indirect and intangible cost estimates to individuals with well managed incontinence.

Most of the reviewed studies on the costs of incontinence do not fully estimate indirect and intangible costs. Those studies which do include indirect costs do not clearly indicate whether such indirect costs have been discounted or excluded from the costs of individuals who are well managed.

Part of the reason for this ambiguity arises from the inherently descriptive nature of cost of illness studies. Cost of illness studies reveal something about society's investment in managing incontinence but nothing about the return on this investment to the individual or society as a whole in terms of the outcomes or effectiveness of treatment and care. The impact of management strategies on quality of life are not directly considered and valued.

An example of a cost-of-illness study is the measurement of the economic burden of managing urinary incontinence in community dwelling patients, including the direct costs of continence pads, laundry, treatment by health professionals, drug costs, indirect costs such as lost productivity and intangibles

costs such as impairment of social and physical activities. Such a study describes the social burden of incontinence in the community based on the collection of data from a diary/questionnaire, taking into account all consumables, and the different use of services to manage incontinence. The aim of this type of study is to highlight the importance of incontinence as a health problem.

2.2.3 Types of Comparative Economic Analyses

Three major types of economic evaluation, which consider the outcomes of interventions, exist:

2.2.3.1 Cost Benefit Analysis (CBA)

Cost Benefit Analysis requires both the resources used and the resultant benefits of different interventions to be expressed in monetary units. This means different interventions can be compared directly and across programs even outside the health sector. The key to the use of CBA is the concept that decisions about the allocation of resources to health (e.g. continence conditions) may not necessarily be the optimal allocation to society as a whole, since it may have "knock-on" effects on other sectors in society outside health. Health care programs may be competing for resources with other programs, not necessarily linked to health. CBA aims to compare all costs and consequences across different interventions and across different sectors and thus allows decisions to be made on the basis of the best return for investment in different sectors. Thus, for example, CBA could be used to answer the question: should resources be allocated to programs aimed at preventing injuries in traffic accidents in young drivers under the age of 25 years or treatment and services aimed at preventing institutional admission for the incontinent elderly living in the community?

It is necessary in CBA to explicitly list all costs and consequences of a particular intervention and attach dollar values to these costs and consequences. This poses a challenge to many health economic evaluations because the monetary value of health and wellbeing outcomes may be difficult to define. There may not be a "market" price for these components of the CBA. This may be due to "imperfections" in the market for health, such as the monopoly held by providers of subsidised health products (e.g. continence aids and equipment): the prices do not truly reflect the costs of these goods. Resources used to manage incontinence, for example, may not be traded on the market, such as the labour of caregivers in the home, or the value of costs for substitutes for continence pads (old sheets and cloths used by some community dwellers). Translating consequences in health to monetary values is far from easy. Due to these difficulties, true Cost Benefit Analyses are very scarce amongst the economic evaluations of health care programmes.

2.2.3.2 Cost-effectiveness Analysis (CEA)

Cost-effectiveness Analysis is used to compare interventions for a particular health problem which may differ in the size of their effect on one or more of the health outcomes. However, since the units of measurement for outcomes must be the same across the interventions being compared, this type of analysis is only practicable and meaningful when comparing interventions by using the same outcomes. This means that if the principal effect on health can be satisfactorily expressed in a single measurement (such as a frequency volume chart or pad test), then the alternative methods for achieving this outcome can be measured by using a CEA. Thus the continence outcomes measurement suite recommended by Project 1 will provide the basis for measuring and valuing the consequences in any CEA in future.

CEA is typically undertaken when a decision has already been made to treat a particular condition. CEA is then carried out to identify the most efficient way of achieving the desired treatment outcomes. CEA is the economic evaluation of choice and the one most frequently used as part of a randomised controlled trial (RCT). The concurrent execution of a RCT and a CEA is of great benefit for a number of reasons. The prospective and large scale collection of information on actual costs of resources used and their variability in RCTs greatly enhances the possibility of their adaptation to other settings. A common format for CEA is to then incorporate the findings on effectiveness, costs and outcomes from several studies, test assumptions by varying the estimated values using sensitivity analyses and use a decision tree model to compare the various pathways of different methods of treatment. The model allows decision makers to break up a complex health problem such as incontinence into its simpler, more manageable component parts, to examine each of the parts in greater detail and take each part into consideration in a logical sequence to make a decision on the best intervention and pathway.

The decision tree is a flow diagram in which the decisions and outcomes are depicted through time from left to right. Each tree has points at which decisions are made concerning which treatment to institute

(called decision nodes), and points at which outcomes from the treatment differ (called chance nodes). At each point, the paths must be exhaustive and mutually exclusive. The Markov model, described by Briggs and Sculpher (1998), is one such decision analytic model. It consists of a decision tree with nodes at which various outcomes are predicted to occur with certain probabilities. Probabilities for each arm as well as the estimates of costs for each outcome and treatment are obtained from linked databases, meta-analyses, randomised trials and expert opinions. A computer program allows a virtual cohort of patients to enter the model and calculates the final outcomes and corresponding costs. Input costs and probabilities can be varied for sensitivity analyses. Such a decision tree and decision analytic model was used by Ramsay (1996) to compare the cost of three alternative treatments for stress incontinence in elderly women in the USA, using the recommended clinical guidelines of the AHCPR (USA Agency for Health Care Policy and Research) (Refer section 2.3.3.4).

2.2.3.3 Cost-utility Analysis (CUA)

Cost-utility analysis can be considered as a form or extension of cost-effectiveness analysis. Like cost-effectiveness analysis, the unit of measurement for the costs of an intervention can be different from that of the outcome in cost-utility analysis. However, unlike cost-effectiveness analysis, cost-utility analysis enables comparison across interventions with quite different outcomes. This is especially the case when interventions cause differences in both the quantity (survival) and the quality of life.

This ability is achieved by seeking to measure the utility of interventions, that is, a universal non-monetary measure of the benefits of interventions. In health care, this has been largely pursued through the development of a single outcome measure that combine quality and duration of life. In this way, health interventions that improve the quality of one's life can be validly compared with interventions that extend one's life.

The most common measures being explored are the Quality Adjusted Life Year (QALY) or the Disability Adjusted Life Year (DALY). Unfortunately, the only study available indicated that such measures do not show marked improvement after treatment of incontinence (Foote et al. 2001). This may present a fundamental problem for workers in the field of urinary and faecal incontinence. The QALY can be used when comparing treatments and programs which compete for scarce health resources, as it is a recognised common yardstick (particularly for workers in fields such as cancer, cardiac surgery and renal dialysis, where death is an important and frequent outcome).

A typical scenario for a CUA would be the outpatient clinics in large teaching hospitals which face a high pressure on the availability of specialist medical staff and resources to treat patients with incontinence. There is a possibility that such patients may be adequately managed either by a Nurse Continence Advisor (NCA) in the outpatient clinic or in the community. A CUA is useful in assessing the difference in both quality of life and the survival in incontinent patients comparing both costs and outcomes of their management in outpatients by an urogynaecologists or NCA, or in the community by the NCA.

2.3 Summary of the Available Publications regarding the Costs of Urinary Incontinence

The following section discusses in greater detail the three main types of studies in the literature review under the headings suggested by Versi et al. 1999: descriptive analyses such as cost of illness studies, comparative analyses or economic evaluations of specific interventions and review articles. Literature dealing with faecal incontinence is dealt with in a separate section.

2.3.1 Overview of Cost of Illness Studies

Three key studies identified during the literature search can be considered, at least in part, cost of illness studies: Hu (1986) from the United States, Clayton et al. (1998) from the United Kingdom and Doran et al. (2001) from Australia. A summary of the studies is presented in Table 5.

Table 5 Cost of illness studies

Author	Population Group	Scope of Costs	Sources of Data

Clayton et al. (1998)	Women (n = 118) referred to an incontinence service, including a sub sample of disabled women. Results not applied to prevalence data to estimate a national cost.	Direct cost of formal services, products and appliances. Indirect cost of informal care and social security. Costs measured over a three-month period.	A semi-structured interview (Service Receipt Schedule) was used to collect information from patients about service, product and appliance utilisation in order to ascertain financial impact of incontinence on patients, carers and costs statutory providers. British National Formulary for drugs, local health trusts for health services, laundry from a consumer magazine, and notional value of informal care.
Doran et al. (2001) Related articles: • Dowell (1999) • Moore (1999) • Simmons (2000) • Moore (2001)	Community dwelling ambulatory women (n = 100) attending an incontinence service with stress, urge or mixed incontinence. Applied to estimated prevalence of community dwelling women over 18 derived from Women's Health Australia project and ABS population data.	No direct costing of a client group was undertaken. The author relies on results of Dowell et al. (1998). Direct personal (pads, laundry) and treatment (consults, investigations, drugs, travel, surgery) costs incurred by the women. Indirect cost of loss of wages incurred through treatment was noted. Depending on cost category the timeframe ranged from 1 week to a year.	A questionnaire (Dowell-Bryant Incontinence Cost Index) was used to collect information from patients about personal incontinence expenditure and treatment expenditure. Retail prices of pads, bed protectors etc. Water and electricity prices and usage guidelines from consumer magazines etc. Treatment costs were a combination of patient expenses, public sector costs and MBS/PBS benefits.
Hu (1986) Related articles: • Hu (1990) • Wagner and Hu (1998) • Hu et al. (2000)	No direct costing of a client group was undertaken. Author relied on results of a number of other studies. Prevalence data based on extrapolation of micro studies in nursing homes and the community and applied to population data for the over 65 age group.	Direct costs of consultations and physical examinations, surgical procedures, drugs, nursing home and community care, rehabilitation, related conditions (e.g. urinary tract infection and fall) and contribution to admission to nursing home and longer hospital stays. Indirect costs of lost leisure and productive effort.	The author derived utilisation and costs from a variety of studies from the US and the UK.

Hu and Clayton drew heavily on other studies to estimate prevalence of incontinence and develop approaches to costing treatment and care. Hu's work has been updated and revised over time (Wagner

and Hu 1998) and more recently extended to the consideration of the overactive bladder (Hu and Wagner, 2000).

Versi et al. (1999) indicated that the costs included in cost of illness studies can be calculated from national statistics where available (top down) or by collecting detailed costs for a cohort of patients and combining them with prevalence estimates (bottom up). Most of the studies reviewed here employed a combination of approaches, including a significant level of extrapolation across population groups and using assumptions regarding the external validity of the detailed costing data.

Hu's (1986) work provided perhaps the first and most comprehensive approach to estimating the direct and indirect costs of incontinence. However, given the amount of data required for his costing framework and the inherent lack of American national data, Hu had to resort to a large number of American and British micro level studies to estimate required costs and utilisation levels. The potential weakness of this approach is that the external validity of the studies is questionable, particularly in relation to the British-based work.

In comparison, both Clayton and Doran drew on actual utilisation and costs reported in a direct survey of a population group more closely aligned to the target population. However, in an apparent trade-off for this improved validity, both studies have a narrower focus than Hu's study in terms of the range of costs, level of modelling and population coverage. For example, Doran's study extrapolated from the previous Australian work of Dowell et al. (1998), in which 100 community dwelling women with mild, moderate or severe incontinence completed an Incontinence Cost Index.

2.3.1.1 The Dowell Bryant Incontinence Cost Index (DBICI)

The DBICI is a detailed questionnaire that measures all direct personal costs of managing incontinence over the preceding week, including pads, linen, laundry costs of washing soiled clothes, dry cleaning costs etc., as well as all medical costs for treatment over the previous 12 months (Dowell et al. 1999). It is designed for administration by a nurse continence advisor – self-administration is not successful. The test-retest reliability of the test has been established and the direct costs correlate strongly with the severity of incontinence, on objective measures. The DBICI is also responsive to change, i.e. reduction in incontinence after treatment is mirrored by reduced direct costs of incontinence.

2.3.1.2 Summary of Cost of Illness Studies

In relation to the collection of cost data in these "cost of illness studies", there are a number of key observations that can be made:

- The focus is on direct costs of treatment and self-care, although Hu does go beyond this to partially consider indirect costs. Dowell et al. did question women about loss of wages, but found that those who were employed did not lose wages due to incontinence nor due to incontinence treatments.
- The estimation of costs pertains only to a sub-set of the population, such as the elderly or women living in the community.
- There is insufficient detail provided on costing methodologies and results.

It was clear from the published literature that very little exists in the way of detailed approaches to constructing and calculating costs of incontinence. The presentation of the costs in the economic evaluation must be detailed and structured in such a way as to more readily answer the following questions:

- What is the specific nature and magnitude of costs borne by individuals and families, other individuals, the government and organisations in seeking to manage the impact of incontinence?
- What is the burden on individuals, society and the economy of unmanaged incontinence?

Versi et al. (1999) described an alternative cost of illness methodology whereby lifetime costs are estimated for a cohort of clients and adjusted for estimated incidence. There is no published study of this kind for incontinence. This form of approach was recently employed by the National Centre for Social and Economic Modelling (NATSEM) in seeking to estimate the five year costs of a hypothetical cohort of people with diabetes between 1995 and 2050 (Walker 2001).

2.3.2 Overview of Comparative Analyses (Economic Evaluation)

The form of economic analysis that has been employed in each of the following studies, if any, is indicated in this report. While the precise requirements for each type of economic evaluation may not have been met in each case, an indication of the nature of the study is given. The categories of the form of economic analysis are:

⇒ Cost of Care Analysis (CA) Similar to Cost of Illness study, no attempt to measure outcomes of the care.

⇒ Cost benefit analysis (CBA).

⇒ Cost-effectiveness analysis (CEA).

⇒ Cost-utility analysis (CUA).

It is noted that the quality of the studies varies significantly (refer to the summary table in Appendix A). A substantial proportion of the published literature concerning the costing of incontinence concerns the evaluation of specific interventions. With the exception of two, these studies involve some form of comparison of the cost of two or more interventions. About two thirds of these studies included assessments of the relative outcomes, impact or effectiveness of the interventions. The studies were identified according to the categories listed above:

- **Cost of Care (no comparative analysis):** Borrie (1992), Korn (1996).
- **Cost Comparison**: Berman (1996), Brown (1998), Coleman (1999), Cummings (1995), Curtis (1997), Dolman (1998), Erikson (1989), Fornaret (1985), Gomes (2000), Kung (1996), McCormick (1990), McGhee (1997), McMurdo (1992), Nordqvist (1984), Ramsey (1996), Sampselle (2000), Schnelle (1998), Sowell (1987), Watson (1990), Weber (2000), Wielink (1997).

2.3.3 Review of Comparative Costing Methods in Current Literature

In line with the requirements of this Project, the following section focuses on the costing methodologies of the studies reviewed. The studies have been categorised according to care setting i.e. Nursing Home, Hospital, Community (rather than population group, intervention or type of economic analysis).

2.3.3.1 Nursing Home Setting

Cost of Care studies include: Borrie (1992), Dolman (2001), Ouslander (1984) and Sowell (1987). Cost-effectiveness analyses include: Cummings (1995), McCormick (1990), McGhee (1997), McMurdo (1992), Nordqvist (1984) and Schnelle (1988).

Common to most of these studies is a costing methodology that includes:

- Number of incontinent episodes are measured.
- Time spent toileting patients or dealing with incontinent episodes is measured.
- Quantity of personal clothing and bed linen soiled is measured.
- Use of urinary drainage devices and disposable pads is measured.
- Cost of nurse time, laundry services and incontinence products are applied.

However only a few of the studies consider the:

- Cost of treating incontinence [McGhee (1997), McMurdo (1992), Nordqvist (1984) – drugs].
- Cost of treating complications of incontinence [Ouslander (1984) – comprehensive – useful, McCormick (1990) – partial – not useful].
- Hypothetical costs associated with institutional placement of patients who might otherwise live at home if they were continent [Wagner and Hu cited in Fantl et al. 1996, Hu (1990) cited Huang et al. (1988)].
- Set up costs of trial intervention [Schnelle (1995) spread over 3 years and depreciation of plant and equipment Schnelle (1988)].

Ouslander (1984, 1982) published seminal studies of nursing home incontinence costs. Although quite early, the work carried out by Ouslander is probably still the most comprehensive study of nursing home costs of incontinence published in the literature. Hu and others continue to cite this work in their cost of illness studies. Ouslander (1984) divided the costs of incontinence into first order (costs of daily management) and second order (costs of managing complications of incontinence) costs. The second order costs were divided into those managed in the nursing home and those managed in an acute hospital.

Similar to other subsequent studies, Ouslander costed incontinence supplies, laundry and labour to estimate first order costs. In considering second order costs, billing data and incidence rates from the literature were used to estimate the costs of three incontinence related complications; skin irritation/ breakdown, urinary tract infection treated in the nursing home and urinary tract infection treated in an acute hospital. Ouslander noted that "incidence rates came from very limited data available in the literature" (1984, p. 72).

Schnelle (1988) compared the costs of prompted voiding to the costs of single pad and bed sheet changes. The timed voiding regime certainly reduced incontinence severity but increased costs. There was no measurement of quality of life or other outcomes to justify the costs. In one of the few randomised controlled trials in this field, McMurdoe et al. (1992) randomised nursing home patients to urinary catheterisation versus continence pads, and costed the nursing time plus consumable costs of each regime. Unfortunately, the majority of patients randomised to catheterisation refused to have the catheter inserted. Costing was performed in a separate group of non-randomised patients who underwent catheterisation for intractable incontinence. This study illustrates the difficulty of performing true randomisation of a consecutive series of incontinent patients: individual management of this complex disorder is often needed. Also, since 1992, the practice of urethral catheterisation solely to manage severe incontinence has fallen into disfavour because of the increased risks of symptomatic urinary tract infection, trauma to the urethral orifice, and irritation of the bladder (trigone) mucosa causing urgency and spasm.

2.3.3.2 Hospital Setting

Cost of Care studies include: Brown (1998), Curtis (1997), Forneret (1985), Gomes (2000), and Korn (1996). Cost-effectiveness analysis includes: Berman (1996), Kung (1996) and Wielink (1997).

Most of the studies employed a fairly similar and straightforward approach to costing the interventions and care being considered. The American studies relied on available billing data provided in the private health system whereas Kung (1996) relied on costing data available in the publicly financed hospital system in Canada. The use of cost versus price (billing) affects the overall findings of these studies.

A summary of the source and range of cost data collected in these studies follows:

- *Sling operations versus cystoscopic collagen injection in women (Berman 1996)[CEA] provides* Hospital billing data – room charges, supplies, pharmacy, diagnostics, theatre, post operative care and physician fees. This study also provides data on outcomes.
- *Artificial urethral sphincter versus collagen injection in post-prostatectomy men (Brown 1998) [CA]* Medicare and Non Medicare fee data for similar range of fees. Pad and undergarment cost from suppliers.
- *Abdominovaginal sling procedure in women (Curtis 1997)* [CA]. Patient charges itemised on the billing statement. Similar range of fees. Aim was to reduce length of stay (LOS) and hence per diem charge. Intermittent self catheterisation was an important method used to limit LOS.
- *Stamey/Pereyra Suspension versus Marshall-Marchetti-Krantz retropubic suspension procedure in women (Forneret 1985)* (outdated study as these procedures are no longer widely used), [CA]. Key intervention change was intermittent self-catheterisation. Charges for hourly operating room time and basic hospital room charges. Physician fees were not included.
- *Artificial urinary sphincter versus transurethral collagen injection in post-prostatectomy men (Gomes 2000)* [CA] provides Collagen costs, skin tests, pads, sphincter hardware.
- *Frequency and type of surgical procedures for stress incontinence (Korn 1996)* [CA]. National Hospital Discharge Survey – ICD-9 procedure codes including 59.3, 59.4, 59.5, 59.6, 59.71 and 59.79 and for women with diagnosis code 625.6, procedure codes 70.50 and 70.51. Given that the survey lacked accuracy to estimate frequencies less than 5000; only the most common operations were included (this problem would not exist with the Australian National Hospital Data Collection, as it is census rather than sample based). Uses Californian Office of State-wide Health Planning records of billing to cost admissions.
- *Laparoscopic versus Abdominal Burch colposuspension procedure in women (Kung 1996)* [CA]. Physician fees from Ontario Schedule of Benefits, nursing costs, drug costs from charts, equipment costs from depreciated purchase prices, overhead costs from local hospital studies.
- *Sacral rhizotomies (neurosurgery) and electrical bladder stimulation versus conventional care in neurological incontinence (Wielink 1997)* [CEA]. Short and long-term costs were considered over a two-year period and extrapolated to 30 years. Costs included hospital care, self care, and travel expenditures. Hospital costs were derived from the financial system of the hospital. Long term costs included treatment of diseases due to lower urinary tract dysfunction. Model for short-term

costs assumed the costs to be continuous over time and were discounted at 5 per cent per annum. This study demonstrated that high cost procedures can be considered more cost-effective if viewed over the longer term and raised a broader issue regarding the appropriate timeframe for economic evaluation of incontinence interventions generally.

Menachem (1995) demonstrated that incontinence cure following colposuspension was time-dependent, with a progressive decline over 10-12 years. If this is the case, then clearly the cost per cure will be significantly affected by the timeframe employed in the economic evaluation of the cost and effectiveness of this procedure. Similarly, Bo (1996) provided some evidence of increased incontinence in women 5 years after participating in a six month intensive pelvic floor muscle exercise program. Drummond noted that trials should have longer follow-up, as some of the changes in the socioeconomic end points may take considerable time to manifest themselves (1997, p. 108).

2.3.3.3 Community Setting

The majority of these studies are CEA: Coleman (1999), Eriksen (1989), McClish (1999), Ramsey (1996), Sampselle (2000), Simons (2000), Weber (2000), with one CUA Foote (2001).

The studies based in community settings tend to be more recent, because only in the last 10 years has evidence accumulated that conservative therapy (which is performed in the community setting, not hospital) is truly effective. Overall, the costing methods employed in these studies were often poorly documented. An overview of each study follows:

- *Coleman et al. (1999)[CEA]* comprised a randomised (by clinic) controlled trial of Chronic Care Clinics seeking to better meet the needs of older persons with chronic illnesses including urinary incontinence. Constraints on sample size limited study power. The research was not able to demonstrate improved management of conditions after 24 months of the intervention. The study did not describe costing methods but did measure the costs of pharmacy, emergency visits, primary care visits and hospital visits.
- *Eriksen & Eiknes (1989) [CEA]* assessed the cost savings of avoiding surgery by patients using electrical pelvic floor stimulation at home. Costs of colposuspension operation were compared with cost of stimulator device and two extra visits to outpatient clinic. Of 55 women awaiting surgery for stress incontinence who had electrostimulation, 56 per cent were either cured (36 per cent) or had slight incontinence (20 per cent) at two-year follow-up. This group consequently avoided surgery. The authors concluded that electrostimulation reduced the need for surgery by 56 per cent in the study population. The authors then costed the social costs of surgery and electro-stimulation. Little detail is given but the costs included: surgery, the cost of six weeks sick leave, including time in hospital based on mean salary and social expenses for the female population, the cost of hospitalisation for the surgery, the cost of stimulation, with cost of two additional outpatient visits. Given that all the women received stimulation, the cost-effectiveness of this intervention is clearly dependent on the success rate of preventing surgery (reducing incontinence to the point where surgery is not undertaken). Therefore, if 1 in every 6.73 (15 per cent) or less treated patients avoids surgery, then stimulation is cost-effective. In the study, 1 in every 1.6 (56 per cent) of the patients avoided surgery, hence stimulation was cost-effective.
- *McClish et al. (1999) [CA]* examined the pad usage of women aged 45 years and older in a community based women's continence program. Daily diaries recorded pad usage by type. Prices were derived from retail stores. The authors found that pad usage and cost were moderately correlated with number of incontinent episodes and condition-specific quality of life but not with age, duration of incontinence, or quantity of fluid lost. The median annual pad cost for all subjects was US$46 (1995) (interquartile range IQR of 3-138).
- *Sampselle et al. (2000) [CEA]* tested the effectiveness of a community nursing evidence-based protocol for incontinent women. This was an interesting study that tested strategies to improve screening for incontinence and to improve outcomes through pelvic floor and bladder training. Costing was limited to self-care (self reported usage and retail price of pads) which fell from US$1.18 per day to US$0.81 per day after treatment.
- *Simons et al. (2000) [CEA]*, used the Dowell Bryant Incontinence Cost Index, discussed earlier in Doran (2001) and Dowell (1999), as a post treatment outcome measure of non-surgical therapy. Reduced leakage after treatment did correlate with reduced direct costs.
- *Weber & Walters (2000) [CEA]* defined a hypothetical patient population and used a decision-analytic model (similar in some respects to Ramsey [1996]) to compare the cost-effectiveness between two pre-operative testing strategies. Costs were estimated for procedures, medical treatment and care related to incontinence and retention. Cost data was derived from US Medical Register by

Medicare DRG and ICD-9 codes and medical services using relative value units. Costs common to both interventions were not estimated.

- *Foote and Moore (2001) [CUA]* measured QALYs in 222 Australian women who underwent five different incontinence treatments. These included a randomised controlled trial of conservative therapy by NCA versus urogynaecologists (n = 145), a comparative trial of laparoscopic versus open colposuspension (n = 65) and a study of women having anticholinergic therapy for urge incontinence (n = 12, subset of a larger randomised controlled trial). Their cost utility analysis revealed that conservative therapy by the NCA was the most cost effective treatment, but the severity of incontinence varied within the three study samples.

2.3.3.4 A study of treatments applicable across all settings

Ramsey (1996) employed an interesting hypothetical cohort analysis to calculate the expected costs of three commonly recommended treatments for stress incontinence in elderly women. Treatments were based on the treatment algorithms described in the Agency for Health Care Policy and Research (AHCPR) urinary incontinence clinical practice guidelines. A decision tree representing these clinical practice guidelines for treatment options and outcomes in urinary incontinence management was constructed. In each arm of therapy in the tree, treatment failures at the end of six months were switched to a different therapy.

The study used a Markov cohort simulation comprising 100 community dwelling women aged 65 years or more with chronic stress incontinence who were initially treated with behavioural, pharmacological or surgical therapy. Markov models are used when a decision process involves risk that is continuous over time and when events may occur more than once. During each risk cycle, patients could move from their initial state of incontinence at home to one of four possible states: (1) Cured (2) Continued incontinence at home (3) Continued incontinence, but moved to nursing home (4) Death. Each Markov simulation was run for 10 years, and determined the total expected costs per person over this 10 year period.

The approach employed in this and the Diabetic study (Walker, 2001) provided a potentially useful basis for the estimation of population costs for alternative interventions (under specified assumptions) over time for a chronic disease state. An additional advantage of such approaches is that the impact or outcomes of alternative interventions can be modelled and incorporated into the estimates.

At present, the AHCPR urinary incontinence clinical practice guidelines have not been validated in terms of Australian management of incontinence. Furthermore, there is insufficient data to flesh out the Markov model. The Ramsay study only considered elderly women with stress incontinence. It would be possible to design a Markov model including the other main types of incontinence (urge incontinence in men and women, overflow incontinence in men and neuropathic incontinence in men and women), but the model would be much more complex. If the model were expanded to include people aged less than 65 (which would be necessary if it were to give a total picture of incontinence costs), then the model would be even more complex.

The Markov model used by Ramsay is also outdated in terms of continence therapy. For example, medical therapy comprised phenylpropanolamine, an alphagonist drug that is no longer available in Australia. Also, the cure rate given for needle suspension surgery (84 per cent) is no longer correct.

2.3.4 Review Articles

Several of the more useful reviews have been referred to throughout this document. Specific mention is made of Versi et al. (1999) as it represents the deliberations of a World Health Organization consensus meeting and provides a very useful overview of cost and economic evaluation of incontinence. Hollywood (1998) did not consider costing issues directly, but was the only article reviewed that dealt specifically with incontinence and general practice. These reviews include Anand et al. (1990), Beckman (1995), Hollywood and O'Dowd (1998), Hu and Wagner (2000), Hu (1990), Kobelt (1997), Kornides and Moore (1999), McGhan (2001), Moore (2001) and Versi et al. (1999).

2.4 Outcomes of Intervention: Benefits, Effectiveness or Utility: Willingness to Pay Studies

The primary focus of this literature review was to explore the costing methodologies used in recent studies about incontinence. The consideration of outcome measures and the assessment of the impact of various interventions are taken up in Project One.

Many of the studies reviewed did seek to measure the outcomes of the interventions. Outcomes measures have included a variety of Quality of Life measures, symptoms of incontinence (e.g. incontinent episodes measured by wetness), and willingness to pay. The willingness to pay studies were all performed in community settings: Gafni (1998), Hu (2000), Johannesson (1997), Kobelt (1997), O'Conor (1998) and Schnelle (1995).

Versi et al. (1999) provided an overview of the main methods employed in economic evaluation methodologies. Particular comment is made here on the willingness to pay method employed in the studies reviewed in the literature. As indicated earlier, willingness to pay is one way economists have sought to value the benefits of interventions in monetary terms. The literature reviewed in this section can therefore be seen to pertain to cost-benefit analyses (CBA).

While Johannesson (1997), Kobelt (1997) and O'Conor (1998) focus on benefit valuation, Schnelle (1995) goes some way to presenting a form of cost-benefit analysis. The three researchers, Johannesson, Kobelt and O'Conor played a central role in the development and application of a willingness to pay methodology to value the benefits or outcomes of interventions for incontinence. The studies by these authors were undertaken in relation to drug interventions and were funded by a pharmaceutical company.

Kobelt (1997) reviewed a number of alternative measures of effectiveness or outcome including quality of life measures, quality adjusted life years and willingness to pay. The author suggested the use of the term "controlled days or nights" or "normal" days and nights as a useful condition-specific measure to express the outcomes for incontinence. Kobelt suggested that willingness to pay could also be used to assess the overall burden of disease on patients as an alternative to Quality of Life measures. Hu (2000) noted that willingness to pay might be used to estimate intangible costs of incontinence.

Johannesson (1997) used the contingent valuation method to measure the willingness to pay of Swedish patients with urge or mixed incontinence for reduced micturitions and leakage episodes. The results demonstrated that the greater the reduction in micturition and leakage and the initial number of micturitions and leakages and income of the patient, the greater the willingness to pay values. The median value for willingness-to-pay was US$27[1] per month for a 25 per cent reduction in micturitions and leakages and US$75 per month for a 50 per cent reduction in micturitions and leakages. The authors do note, however, that the results are based on hypothetical questions and real behaviour is needed to establish the validity of the method.

O'Conor (1998) sought to replicate the Swedish study based on patients in the United States. Although the authors report similar results generally, unlike the Swedish study, they were not able to demonstrate that willingness to pay increased with the initial level of micturitions and leakages.

Schnelle (1995) employed a quasi form of willingness to pay methodology in seeking to place a monetary value on the benefits of functional incidental training and prompted voiding of residents in a nursing home setting. He did this by asking residents and families (for demented residents) to compare services of known cost to the interventions or outcomes of unknown value. The value of the interventions was then estimated by comparing the intervention preference ratings to ratings for services of known cost.

Ramsey (2001) noted that "existing data supports the view that a general measure of quality of life, such as utilities or willingness-to-pay, is more comprehensive and accurate than specific clinical endpoints such as pad weights or frequency of symptoms".

There are two overriding concerns about the use of willingness to pay methodologies in economic evaluation in the current literature:

- There are significant differences between hypothetical and actual valuation. These differences are neither predictable nor uniform.
- Willingness to pay is related to ability to pay and hence issues of equity arise in the valuation of outcomes. That is, the value of services to lower socio-economic groups is likely to be estimated below that for higher socioeconomic groups. Johannesson (1997) and others have shown that willingness to pay increases with income.

One benefit of willingness to pay is that patients are able to indicate a measure of intangible costs but these remain theoretical.

2.5 Review of Faecal Incontinence Literature

Only two articles specifying costs of faecal incontinence were identified in the literature review. Surprisingly, given the likely relative prevalence, only one article specifically addressed faecal (and

urinary) incontinence in nursing home settings – relating directly to older people (Borrie 1992). This article was reviewed in the urinary incontinence section of this paper.

- *Mellgren (1998)* provided a very useful overview of current practice and the state of play in terms of prevalence estimates, costing and economic evaluation. This is clearly an under-researched area. The aim of this study was to determine the long-term costs associated with the management and treatment of anal incontinence related to obstetric injuries. Economic data was very scanty in this report.
- *Buttafuoco (2000)* assessed the outcomes and medical costs of patients treated by pelvic floor repair for faecal incontinence. The majority of the incontinence (75 per cent) was caused by obstetric trauma. Costs were based on United Kingdom National Health Service cost estimates and covered the cost of the initial operation and repeat operations and outpatient visits. The costs of evaluation, hospital treatment and personal care were estimated from billing data, the United States national inpatient profile database and client survey of pad usage.

A helpful editorial was provided to this article, outlining some of the issues with the costing in the study, including the omission of anaesthesia charges, costs of primarily repaired sphincter injuries, indirect costs of lots productivity and disability, short follow-up period and the use of charges not costs. Sampselle noted that given the substantial costs of anal incontinence, the "prevention of sphincter injury during child birth should be an achievable goal" (Sampselle, 1998, p. 865).

1. 1997 US$

Section 3. Implications for Future Costing Methodologies

Regardless of the approach taken, building a comprehensive costing methodology for incontinence in Australia will require the identification of key cost and service utilisation data. Following the completion of the literature review, some implications for the proposed pilot studies in Project Two and for future field trials were examined.

3.1 Cost and utilisation of hospital services attributable to incontinence

Clearly, in seeking to place a value on the costs of hospital care, consideration needs to be given to the costs borne by consumers, government and private sector. Out of pocket costs and the remuneration of doctors treating private patients in both public and private hospitals are specific issues that need to be taken into account in any methodology.

3.1.1 Patients admitted to Acute Hospitals to treat incontinence as a Primary Diagnosis.

The principal diagnosis and procedure in the morbidity collection should relate to incontinence and be able to be identified by the relevant International Classification of Diseases (ICD) codes. These episodes will then be allocated a specific incontinence AR-DRG. This type of approach has been carried out by Korn and Learman (1996), who determined the frequency and cost of acute admissions for surgical intervention of stress urinary incontinence by reviewing national hospital discharge data and appropriate ICD codes. Wagner and Hu (1998) also performed a similar analysis, to confirm the validity of treatment rates in the earlier study by Hu (1986).

The literature search did not identify an Australian study that sought to quantify the rate and cost of acute, post acute and sub acute hospital treatment of incontinence. A research methodology could be quite readily developed using the National Hospital Cost Data Collection and other sources. This could be carried out as part of an overall approach to costing incontinence in Australia and would be an essential part of constructing a Markov Model, (see Section 16.5, Recommended Study #2).

For the acute inpatient setting, costing information could be obtained from the National Hospital Cost Data Collection for the average cost of incontinence-specific AR-DRGs. The challenge of estimating private patient medical and diagnostic costs will need to be addressed. Jackson (2000) provided an overview of the various approaches to estimating the cost of inpatient care in Australia and their appropriateness to specific applications. The pilot study using AR-DRGS to study patients admitted with incontinence as a primary diagnosis is contained in Section 12.

3.1.2 Patients admitted to treat conditions associated with incontinence (falls, urinary tract infection, skin breakdowns) – incontinence as a Secondary Diagnosis.

Researchers such as Hu (1986) have sought to quantify the "consequential" treatment costs of incontinence. Ouslander (1984) in a similar vein described the "second order" costs on managing the complications of incontinence. Hu (1990) pointed out that "the cost of incontinence-related health services have been studied by numerous authors but the amount of incontinence-related health care utilisation has not been systematically reported" (p. 293).

The literature search did not identify an Australian study that sought to quantify the rate and cost of acute, post acute and sub acute hospital treatment of "second order" costs of incontinence. The pilot study which surveyed DRG classification and cost implications of patients having a secondary diagnosis of incontinence is contained in 11.4.

3.1.3 Patients admitted to Acute Hospitals for unrelated reasons, but who have incontinence as a Secondary Diagnosis (extended stays or additional care to manage incontinence during admission)

Katz (1982) as cited by Hu (1986) indicated that "as much as an additional nine days during a 12 month period, may be attributable to incontinence" (p. 682). No recent or Australian study was identified during the literature review to validate this earlier work. Hu (1990) and Wagner and Hu (1998) relied on work by Katz (1982). In a recent study by Chu and Pei (1999), bivariate analysis demonstrated that urinary and faecal incontinence were significant risk factors for emergency re-admission to hospital, along with the existence of an institutional carer, adverse drug reaction, poor mobility, previous utilisation of community nurse services and a number of other chronic conditions, but little cost data was provided.

3.1.4 Cost of non-admitted services at public and private hospitals (outpatient and emergency department services)

The only study in the literature review that attempted to provide cost data in this area was Sampselle et al. (2000), regarding early detection and simple conserv uction in surgical day stays, emergency department, and urology registrar time is obvious. The attendances to the Pelvic Floor Unit were accommodated within existing infrastructure and nursing hours. After completion of the First Report, one of the project team published data on a RCT of conservative therapy by a nurse continence advisor versus an urogynaecologist, showing that the NCA achieved equivalent cure at much lower cost (Moore et al. 2003).

It should be noted that in the United States, ambulatory care includes same day admissions and outpatient services which are usually provided by physicians as private consultations in rooms rather than as part of the hospital services. Therefore, American estimates of ambulatory care cost and utilisation for incontinence have very limited applicability to Australia.

3.1.5 Patients admitted for Sub-acute and Non-acute Care, when Incontinence is not the Primary Diagnosis

For sub-acute and non-acute care, the Australian National Sub-Acute and Non-Acute Patient Classification (AN-SNAP) is relevant. It includes five Case Types: 1. Palliative Care 2. Rehabilitation 3. Psychogeriatric 4. Geriatric Evaluation and Management 5. Maintenance Care. The classification covers four Episode Types (or care settings): Overnight episodes; Same Day episodes; Outpatient episodes and Community episodes (Eagar et al. 1997).

The AN-SNAP classification was developed by the Centre for Health Service Development, University of Wollongong, as part of a large study undertaken in 1996. This study involved 104 Australian and New Zealand sites collecting a detailed clinical and service utilisation profile for 30,604 episodes of care over three months (Eagar at al. 1997).

For the service utilisation profile, information was collected about nursing and allied health staff time, aids and appliances, other goods and services, to cost the episode of care (Eagar at al. 1997). This information was used to develop average costs for each AN-SNAP class. Although there are no AN-SNAP classes specifically for incontinence, the methodology used in this study for obtaining resource utilisation information could be useful to develop a framework for costing continence conditions. The Functional Independence Measure (FIM) was collected in this study for Rehabilitation and Geriatric Evaluation and Management patients. Two of the items of the FIM relate to continence conditions – bladder management and bowel management. Subsequently, members of the project team obtained retrospective information from this study to determine whether there were cost differences for patients with, and without, continence conditions, identified by the two relevant FIM items (see Section 12 of this document).

3.2 Cost and utilisation of residential care services attributable to incontinence

The additional cost of incontinence management in the residential aged care setting was well researched by Ouslander in 1982 and 1984. With the introduction of Home Care Packages and Quick Response Teams, all of which tend to keep elderly Australian patients at home, this work needs to be revised in the Australian context, which formed one of the Pilot Projects (see 6.3 of this document).

The cost of managing consequential conditions of people with incontinence in residential aged care needs to be studied in the Australian context. These include the additional costs of managing complications resulting from incontinence such as skin conditions and urinary tract infections. Any study would need to address the difficulty of separating the costs of complications from the costs of usual patient care.

3.3 Cost and utilisation of community care services attributable to incontinence

Patients suffering from incontinence who live at home and utilize community care services need to be measured. These comprise:

- Formal community care costs–Home and Community Care (HACC), general practitioner and specialist consultations, community-based incontinence clinics (the Royal District Nursing Services in South Australia already cost these services).
- Spouse and other carer costs.
- CRAGS Continence Services.
- Community Centre Based Physiotherapists.
- Community Centre Based Nurse Continence Advisors.
- General Practitioner Consultations.

One substudy of the Project subsequently investigated incontinence costs in patients served by CRAGS Continence Services (see Section 10). As is evident from the Third Progress Report (Section 16), full measurement of these community services has proved to be very difficult.

3.4 Personal cost of care of individuals with incontinence

The direct personal costs of managing urinary and faecal incontinence can impose a major burden upon sufferers. These include:

- Pads.
- Drugs – although this may be considered a Treatment Cost unless referring to Over the Counter medications.
- Laundry costs for washing of urine-soaked garments.
- Cleaning costs for urine leaking onto carpets and couches etc.

Although Dowell et al. (1999) did measure personal costs of urinary incontinence in 100 community dwelling women, the DBICI test should be performed in a sample of non-community dwelling women, a sample of men, and a sample of patients with faecal incontinence.

In the pilot study of patients living in hostel accommodation (Section 7), attempts were made to administer the DBICI to determine whether this measurement tool could be applied in hostel-dwelling women (Refer APPENDIX F – Additional Notes on Hostel Residents).

Section 4. Summary and Preliminary Recommendations: Selection of Economic Approaches to Incontinence in Australia

4.1 Summary of the Literature Review

Overall, the literature reveals that the current level of economic analysis of incontinence and its associated costs is low. As such, the literature does not enable a clear and coherent direction for Australia in identifying and developing an approach to the economic and cost evaluation of incontinence. However, a number of pieces of work have been undertaken overseas and locally that are worthy of note as this matter is considered further and a framework for research in Australia is developed.

Hu (1986) and subsequent work provides the most comprehensive and coherent approach to costing the burden of incontinence. However, it is still limited in scope both in terms of population covered (e.g. younger cohorts) and costs incurred (e.g. intangibles).

The papers by Dowell et al. (1999) and others provide a useful and validated survey instrument to measure the direct personal and medical costs of incontinence on a bottom-up basis. Comparison with the approach adopted by Clayton et al. (1998) is warranted if this instrument is to be refined and applied more broadly.

Identification of the prevalence and incidence of incontinence was not a primary focus of this Project. However, sound and comprehensive estimates of such will be required across settings and populations to enable a "whole of society" assessment. Australian studies reviewed in this research were largely limited to available prevalence estimates of urinary incontinence of community dwelling women. The Australian Institute of Health and Welfare is currently undertaking projects to review data sources, prevalence and burden of disease estimates for continence conditions.

The larger proportion of literature reviewed was taken up with micro-costing studies within particular care settings, particularly those related to acute hospitals and residential aged care. A seminal piece of work in the area of aged care is by Ouslander and Kane (1984). While quite dated, the methodology is relatively sound and incorporated into the recent work of many leading commentators in this area. Kung et al. (1996) provide a good example of the range of economic evaluations in the hospital sector.

Of particular note, is the dearth of Australian based studies focussed on the micro-costing of incontinence in specific settings and populations. If Australia is to identify the best buys across the prevention-treatment spectrum, then valid economic studies are required to reflect the Australian service system and associated funding arrangements. The researchers provide pilot studies in a range of incontinence settings in the Second Report.

A number of other studies considered during the review are worthy of note. Ramsey et al. (1996) is an interesting piece of work given the more unusual but potentially useful approach employed to model costs and outcome in relation to practice guidelines. Wielink et al. (1997) is significant as the longer-term view taken illustrates out how cost-effectiveness assessments or ranking can alter over time.

Three research reports by Johanesson, Kobelt and O'Conor (1997, 1997, 1998) focussed attention on the valuation of outcomes through "willingness to pay" analysis. The usefulness of such an approach in the Australian research context is worth further consideration alongside other measures of outcome that also allow broader comparisons, including measures of Disability Adjusted Life Years (DALYs) and Quality Adjusted Life Years (QALYs).

The purpose is to make recommendations about the most relevant approach and methodologies for a framework for economic evaluation, prior to the field trials in Project 3. The following section identifies the approaches and describes the theoretical framework, the pilot studies of patients with continence conditions informing the framework in the acute hospital, non-acute hospital and community health care settings.

4.2 Theoretical Aspects

The conceptual framework of economic evaluation differs according to the type of decisions in question, intended purpose of the analysis, the practical measurement challenges and the perspective of the analyst. If the perspective places great emphasis on the value that the individual places on outcomes,

the total value of the consequences including willingness-to-pay, patient utility not directly related to the health outcome (e.g. reassurance) and benefits accruing to the patient, family, health and other sectors would need to be accounted for.

From the perspective of the allocation of the health sector budget, only health sector resources need be considered with the health improvements gained; willingness-to-pay valuations are not used since they reflect non-health attributes not funded from the health budget. From a broad societal perspective, costs include resources consumed in the health sector and other public and private agencies, costs incurred by the patient and their families and employers. Benefits from the societal perspective encompass not only improvement in the patient's health state, but include costs savings across different government and non-government agencies or providers.

Because of the different forms which economic evaluations can take due to these varying perspectives and objectives, it is difficult to prescribe a single standard form of economic evaluation. The perspective from a single setting or institutional framework may be too restrictive in the context of making decisions on resource allocation within a constrained health budget. A broader societal perspective allows consideration by various provider and funding groups of the effects on resources across different settings. This is particularly relevant for economic evaluations of continence conditions.

The direct personal costs of incontinence, purchase of pads etc., are born directly by the patients themselves. Any move to reduce this burden may shift costs from the patients to the government. The direct treatment costs of incontinence, on the other hand, are currently borne by the Commonwealth Government (GP visits, community nurses, pharmaceutical subsidies, nursing home care), the State Governments (hospital admissions or outpatient visits for incontinence treatments), and the patient (out of pocket or "gap" components of all of the above). In a position paper in press, the Continence Foundation of Australia documented the costs of continence appliances to government and individuals, noting the considerable variations in the administration, eligibility criteria, types of product assistance and subsidy amounts of these products across the states. The authors recommended a number of changes in the way subsidy schemes could improve access to the schemes and reduce operating costs (see APPENDIX B – Excepts from Continence Foundation of Australia Position Paper – towards an Equitable National Scheme for Continence Products).

Furthermore, up to 50 per cent of all nursing home residents are incontinent, and the Commonwealth Government must bear these costs. By better understanding what interventions can best help to detect, prevent, treat or manage incontinence, government has the potential to more effectively prevent incontinence and improve the quality of life of those already suffering from incontinence without significant injections of funding.

As already described in Section 1.4, it is not known whether early intervention at the stage of mild or even "latent" incontinence (i.e. that which exists but does not disturb the patient hygienically or socially) can prevent progression to severe incontinence, that might precipitate nursing home admission in later life. The Project Two Team is aware that the Commonwealth has commissioned a study of ACAT data (J. Pearson, personal communication) regarding incontinence as a direct precipitating factor leading to nursing home admission. If this study indicates that incontinence is a significant relative risk factor for nursing home admission in Australia, then curing (or at least treating) incontinence in elderly community dwelling men and women will be, by definition, a cost-effective treatment.

A cost of illness estimation of continence management could enable policy makers to obtain an appreciation of the overall care burden of the condition vis-a-vis other conditions. Further, an understanding of the relative contributions to these costs made by patients, their carers and the various levels of government could be given. This would also provide a base-line against which the effectiveness of interventions could be measured.

However, such studies will not be able to give any indication of the return on this investment in incontinence management or what impact marginal changes in investment may have on incontinence outcomes. A good understanding of the utilisation and relative cost-effectiveness of the major categories of interventions is required to do this.

From a review of the various approaches to priority setting in the literature, and our ongoing preliminary investigations, our team suggest the following possible approach for an economic analysis of the costs of incontinence in Australia.

One potentially useful approach for guiding research on incontinence could be derived from the Health Benefit and Resource Group work coming out of the UK and more recently in Australia (Segal, 2001).

A matrix approach can be used to identify the various populations, interventions, resources required and outcomes for various condition stage/target groups.

For example:

- At risk.
- Identification of early stage incontinence.
- Acute Care.
- Ongoing Management.

By populating a matrix of this kind with studies from Australia and overseas, the capacity to develop a notion of what are the "best buys" could be progressively developed and decisions could be made regarding the relative investment in prevention and curative interventions.

The development of guidelines and protocols could also be pursued to help guide practice and compare with the costs and outcomes of current practice at a population level.

The AHCPR in the US published a clinical practice guideline to address the problem of acute and chronic urinary incontinence in 1992 with update in 1996. The guidelines were developed by a panel of experts and provide algorithms to aid clinicians in diagnosing and managing adults with incontinence. As discussed earlier, Ramsey (1996) used these guidelines to develop a decision analysis model (a Markov model) for estimating the expected cost and outcomes of the most common treatments for chronic stress incontinence. This work could provide a potentially useful approach to modelling estimated costs of incontinence management in Australia; including policy decisions regarding various alternative service investment strategies (refer Section 16).

Beckman (1995) pointed out that the AHCPR guidelines claim that if the clinical practice guidelines are followed for stress and overflow incontinence there would be a saving of US$83–105 per outpatient and $535–1025 inpatient episode (1995, p 242). Similar estimates for Australia in 2001 could inform future decisions.

4.3 Building Blocks for Australia

4.3.1 Prevention or Early Detection Phase

As regards faecal incontinence, pregnancy and the postpartum period, a few studies have considered the benefits of early detection and primary care management in the puerperium, but none of these studies provided any cost data whatsoever (and thus have not been included in the literature review). However, we believe that a study of such interventions that included costs of early treatment versus costs of usual management (simple leaflets given out in postnatal wards) would be extremely useful. Such data could provide information about the cost per case of urinary incontinence prevented. A randomised controlled trial or a pragmatic management comparison in two separate units would both be informative.

Faecal incontinence should be preventable by appropriate prevention of obstetric sphincter injury but the scope of such a study may be beyond the remit of Project 3 (field trials).

4.3.2 Pilot Projects which were carried out during Part Two of the current Project

4.3.2.1 Incontinence in the Acute Care Setting

Pilot studies tracked the costs of acute admissions in patients who suffer from incontinence. These comprised: *i)* patients admitted for surgery to correct incontinence (primary DRG = incontinence) *ii)* patients admitted with another primary DRG but found to be incontinent, when consultation was requested with a Nurse Continence Advisor by the ward staff. A computer-simulated modelling exercise will also be undertaken, using Trendstar software, to examine the effects of incontinence upon a range of primary DRG's, in the St. George Hospital *iii)* a second pilot study was undertaken regarding the costs of investigating and managing patients admitted to the Acute Hospital for other reasons but found to be incontinent.

4.3.2.2 Incontinence in the Chronic Care Setting

At the time of the First Report, three strands of investigation were under way: *i)* A "cost of illness" framework for data collection was undertaken in the Illawarra region for patients with neurological incontinence in a Rehabilitation setting. The daily cost of incontinence management was assessed along with the FIM score assessments. *ii)* Computerised data already collected for the SNAP project in 1996 was revisited, to see whether a subset of SNAP codes may be assessed to the presence or absence of incontinence. This would help to decide whether SNAP coding methodology could be utilized in Project 3 to specifically focus upon incontinence in a prospective study. *iii)* Finally, a pilot study for assessment of incontinence costs in the nursing home/nursing hostel environment was under way at Sutherland Hospital, specifically focussing upon patients with dementia and upon men with incontinence.

4.3.2.3 Incontinence in the Community Setting

A community based pilot study of patient costs was performed, involving 20 consecutive patients undergoing home assessment by a nurse continence advisor. The Dowell-Bryant Incontinence Cost Index data was collected along with all costs of the first visit itself. This was used to assess what further assessment of the costs of community-based acute care should be undertaken in the proposed field trials.

In summary, the primary task was to collect cost data across the six client groups specified in the tender document across all clinical settings. There is insufficient evidence in the literature to support a single recommended approach to the economic evaluation of continence conditions in Australia. The economic questions to be addressed are likely to be different for the various types of incontinence.

While the studies in the literature review add to the body of knowledge in this area, there is a lack of potential application of the findings to the Australian context due to a number of specific factors. American costs are based on billing or prices charged to patients; such costs do not reflect the costs of resources used in caring for patients as they would in the Australian health care system. Differences in clinical practice such as the provision of ambulatory care in the United States in private consulting rooms rather than hospital outpatient clinics impact directly on the use of American data in the Australian setting.

There is a lack of estimates of current prevalence and costs of incontinence against which the success of interventions can be measured. There is a need for studies to identify costs of known effective strategies, to ascertain where costs are borne and to estimate the amount of preventable incontinence. At this time it was considered premature to make definite recommendations about economic studies and costing strategies, and several were discussed at the Economic Workshop held on 29 October 2001 (refer Appendix J).

4.4 Conclusion

There were a number of factors to be considered before more definitive recommendations could be made. Firstly, the discussions with experts at the Stakeholders" Workshop on the 29th of October needed to be incorporated together with the issues identified in the literature review. These discussions included the adequacy of both existing and currently being collected data, continuing data gaps, and the methodological problems already discussed. The proceedings/minutes of the Stakeholders Workshop help on 29 October 2001 are presented as Appendix J – the very last Appendix – and give an overview of some important discussions that took place between health economists and continence clinicians prior to the commencement of the pilot studies. Issues such as "Burden of Disease", and the definitions of "Incontinence" to be used in certain pilot study settings, were clarified and then incorporated into the pilot study methodology. The discussions that occurred at this Stakeholders Meeting also influenced several of the final recommendations given in this report. The reader is therefore strongly encouraged to look through the proceedings of this Meeting, which are the last appendix in this document.

A second consideration was the length of time required for analysis of the results of the pilot studies, and recommendations for larger studies which will flow from this analysis. A further consideration was the appropriateness and feasibility of duplicating one or more of the international studies (e.g. Ramsey, 1996) and the extent to which the results of such a study could inform Australian policy. All these considerations, together with the resource implications of the recommendations, are further developed in the Third Report (refer Section 16).

Section 5. "The Burden of Disease"

Excerpts from Continence Foundation of Australia Position Paper – Towards an Equitable National Scheme for Continence Products

The Continence Foundation of Australia conducted an assessment of national distribution schemes for continence Aids and Appliances. The full text of this document is available from the Continence Journal of Australia [Kelly et al. 2001]. The Project team believes that the material included in Appendix B, from the CFA document, is the only published material that relates to the sector of the population that experiences the largest Burden of Disease, e.g. those with neuropathic incontinence who are home-dwelling. As shown in Table 57, of Appendix J, patients with neuropathic incontinence occupy a relatively small proportion of the Australian population, but because they are largely incurable, such patients account for a large portion of the "Burden" of the disease of incontinence.

Detailed examples are given in Appendix B of patients with neuropathic incontinence, taken from case histories prepared by Nurse Continence Advisors for the CFA report. The Project Team strongly encourages readers to peruse Appendix B at this point, as it is very informative. A brief summary is given here.

The main issue that emerges from the full report [Kelly et al. 2001] is that home dwelling patients with neuropathic incontinence often suffer from a life-long disease, which cannot be cured. As a result, they spend quite large sums of money for pads, appliances, medications and laundry. Their relentless incontinence carries a tremendous "Burden of Disease". This burden extends to their families who care for them at home. Such families provide 24 hour care, in changing their pads/bed linen/adult diapers. These care requirements also have a major financial impact upon the families of the affected patients. Although subsidy schemes are available to help relieve the financial burden (CAAS and PADP), the amount of funding given to each individual is often inadequate because the costs are so great. The lack of adequate subsidy imposes further distress to the families concerned.

For example, one of the main issues appears to be that the CAAS scheme for incontinence aids is only available to patients under age 65. However, neuropathic incontinence (e.g. Paraplegia, Case 1, Multiple Sclerosis, Case 2, Steele Richardson Syndrome, Case 3, and Cerebral Palsy, Case 8) does not cease at age 65. Details of personal cost issues in these cases are provided in Appendix B.

A second problem is that paediatric patients with neuropathic incontinence are often not eligible for subsidy (Case 3).

Thirdly, patients with post-irradiation faecal incontinence after bowel cancer often cannot obtain sufficient subsidy for their continence needs (Case 4).

Patients with totally debilitating neuropathic incontinence (e.g. Microcephaly, Case 5) cannot obtain total subsidy that approaches their continence needs. The "burden of disease" then extends to their carers, who struggle to maintain these patients at home rather than institutionalize them (which would provide all their continence costs).

Patients with post-surgical neurological complications (Case 10) also suffer from lifelong incontinence, but the personal costs in such cases can be very large. Such cases also have implications for the current medico-legal climate.

Finally, patients with a chronic neurological illness (refer Case 11, Parkinson's disease and dementia) who remain living at home incur tremendous costs for their personal incontinence. If they were institutionalized these costs would be met by the institution, but there is no mechanism whereby those who remain home-dwelling can receive appropriate subsidy for their incontinence. The costs are displayed in Table 6.

Whether such neurologically impaired patients should or should not receive full subsidy is not the point of this Section of the report. Appendix B is included because it is the only published information that the project team could find about the annual costs of incontinence for this type of patient. See Table 6 below:

Table 6 Incontinence Costs for Sample patients with neuropathic diseases

Case 1	Paraplegia	$1,000 p.a.
Case 2	Multiple Sclerosis	$3,000 p.a.

Case 3	Congenital Cloaca Syndrome	$1,500 p.a.
Case 4	Post bowel cancer irradiation	N/A
Case 5	Microcephaly	N/A
Case 6	Steele Richardson Syndrome	$1,100 p.a.
Case 7	Quadriplegia	$2,200 p.a.
Case 8	Cerebral Palsy	$1,200 p.a.
Case 9	Spinal Abscess Post-surgical spinal damage	N/A $1,850 p.a.
Case 10	Parkinson's and Dementia	$2,850 p.a.

The Project Team believes that the problem of home dwelling patients with neuropathic incontinence is severely under-researched and under-reported. The only aspect of this problem covered in the published literature was the study of the costs of sacral rhizotomy versus electrical bladder stimulation (Wielink et al. 1997). Neuropathic incontinence is associated with a large Burden of Disease and severe costs to the patient and the Australian health care system.

Second Progress Report

Section 6. An Overview of The Pilot Studies

6.1 Introduction

As described in the original tender document RFT 55/0001, the purpose of this Second Progress Report was to provide a draft framework for the economic and cost evaluation for continence conditions. The aim was to consider the six target groups, the different types of treatment interventions and the range of care settings.

The literature review (First Report) revealed a striking lack of data or useful publications on the subject of the cost of incontinence. Therefore, seven pilot studies were undertaken to make preliminary attempts to gather some data about the cost of incontinence for these target groups/treatments/settings. The main body of the present report describes the methods and results for these pilot studies.

Two main costing approaches were taken: face to face "patient-level" recording of costs, and use of the current casemix classification systems to accumulate prospectively or analyse retrospectively, the presently available costing data. Thirdly, a census of all incontinence in one acute care teaching hospital on one day was undertaken, as without this data it is difficult to assess the magnitude of the problem in the acute care setting.

Several methodological problems were encountered during these pilot studies, which are discussed. Problems with the definition of urinary faecal incontinence, and coding for these conditions within the Casemix system, are discussed. Then, in the final Discussion section, recommendations are made about how to construct a feasible framework for Economic and Cost Evaluation of continence conditions. An overview of the adequacy of currently available methods to measure cost of incontinence is given. The issue of the perspective from which one undertakes an economic analysis (e.g. patient as payer, society as payer) is briefly considered.

1. Patient level costing studies

a. Substudy 1: Costing study in the chronic setting (Sutherland and Port Kembla Hospitals, John Paul and Thomas Holt Memorial Villages).

b. Substudy 2: Costing study in the acute setting – Nurse Continence Advisor referrals at St. George Hospital.

c. Substudy 3: Costing study in the acute setting – Pelvic Floor Outpatient Unit.

d. Substudy 4: Dowell-Bryant Incontinence Cost Index (DBICI) – Community-dwelling elderly women.

2. Casemix analyses

a. Substudy 5: Effects of incontinence conditions in the acute setting on Diagnosis Related Group (DRG) assignment.

b. Substudy 6: Analysis of the AN-SNAP database with respect to continence conditions.

c. Substudy 7: Analysis of relationship between Functional Independence Measure (FIM) and definitions of incontinence.

3. Prevalence study

a. Substudy 8: Study of prevalence of incontinence in the acute setting.

The report begins by describing the conduct and outcomes of the small pilot studies relating to the adequacy of cost and utilisation data currently collected. The preliminary analysis of data accuracy is summarised and recommendations made as to their suitability for economic analysis. The incorporation of these data in micro- and macroeconomic frameworks is then described. On the basis of these findings, a detailed framework for the subsequent analysis of incontinence costs is provided together with advice to the Department concerning liaison and consultations with the project team developing an outcome measurement suite for continence conditions. All results in the studies of Project Two are preliminary and pilot in nature. There is a need for repeat, larger studies with larger sample sizes using agreed outcome measures.

The first section commences with the rationale for the selection of pilot study sites and their description, followed by the definition of incontinence used in these pilot studies. The eight interrelated substudies are described in turn. Issues with the data collection and implications for costing studies for subsequent economic evaluations of continence conditions follow.

6.2 Methodology Description of Pilot Study Sites

6.2.1 Selection of Pilot Study Sites

The pilot study sites for the cost and utilisation data were selected according to criteria described in the original tender document. These criteria were:

Client subgroup

The patient subgroups considered were

- Women of childbearing age.
- Men and women at risk of developing incontinence.
- The elderly.
- The frail elderly.
- Dementia patients .
- Patients with incontinence associated with neurological conditions.

Treatment settings

Three treatment settings were used for sampling purposes:

1. *Acute care setting:* St. George Hospital
2. *Chronic care setting:* Sutherland Hospital, Port Kembla Hospital, John Paul Village and Thomas Holt Memorial Village
3. *Community setting:* Northern Sydney Area Health Service Aged Care and Rehabilitation Unit.

There were broadly three methods of cost and utilisation data collection:

A. Patient level costing

Bottom-up cost information was collected using four methods. First, a daily hourly log of staff time and resource consumption was captured at the four sites in the chronic care setting (Sutherland Hospital, Port Kembla Hospital, John Paul Village Nursing Home and Hostel, Thomas Holt Memorial Village Nursing Home and Hostel). Patients in these sites were the elderly, frail elderly, dementia patients and patients with incontinence associated with neurological conditions. Second, in the acute care setting at St. George Hospital, the management, care and follow-up of patients seen by a Nurse Continence Advisor (NCA) were documented. These were acute patients who were admitted for the treatment of conditions other than incontinence but were found to be incontinent, when consultation was requested with a NCA by the ward staff. Average costs were assigned to these patients by timing a list of usual tasks associated with their care thus providing unit costs per task. Third, in the acute care setting at St. George Hospital, the average costs of managing incontinence in outpatients at the Pelvic Floor Unit were estimated. Finally, the Dowell-Bryant Incontinence Cost Index (DBICI), an instrument developed to measure the total costs of urinary incontinence (Dowell et al. 1999), was administered by Caroline Dowell, the Nurse Continence Consultant attached to the Northern Sydney Area Health Service Aged Care and Rehabilitation Unit, to community dwelling patients in the course of her community visits.

B. Casemix analyses

Casemix analyses were undertaken in three forms. First, in the acute care setting, a computer-simulated modelling exercise was conducted to examine the effects of incontinence upon a range of Diagnosis Related Groups (DRGs), using software in the St. George Hospital Department of Clinical Information. Second, in the acute care setting, the AR-DRG coding of incontinence as a secondary diagnosis was examined by retrieving the medical records of patients referred to the Nurse Continence Advisors at St. George Hospital. Third, in the chronic care setting, information on the costs of incontinence in sub-acute and non-acute patients was analysed using the Australian National Sub-Acute and Non-Acute Patient (AN-SNAP) Classification. This analysis

was undertaken by the project team member, Irenie Smoker, in conjunction with Janette Green from the Centre for Health Service Development at the University of Wollongong.

C. St. George Hospital Incontinence Census

A census was performed at St. George Hospital on a single day by five members of the project team to determine the prevalence of urinary or faecal incontinence and the use of continence pads in admitted into an acute hospital.

The methods, results and discussion of each substudy are presented separately for each pilot study, but overall discussion and conclusions are presented at the end of this Second Progress Report.

6.2.1.1 Overhead Costs in Different Settings

The patient level costing studies measured direct costs (staff and consumables). However, since the objective of measuring costs is to estimate the ***total*** value of resources used in caring for the incontinent patient, in principle, fixed or overhead costs should be included in cost estimates. Whilst this Project acknowledges the importance of identifying measuring all of the costs of providing services for incontinent patients, it may not be possible or, in some cases be necessary to measure and value all costs. However, full identification of relevant cost items should be provided. In addition to direct costs, these include overhead costs and costs incurred by the patients themselves and their families and carers. The later costs are expenses paid in securing services from the private sector particularly from home care support services such as private nursing agencies and home care, and out-of-pocket expenses and time lost from work seeking treatment. The proposed field trials will need to take these additional categories of costs into consideration. The following section gives an overview of the issues surrounding the measurement and valuation of overhead costs and costs borne by the patient and the community.

Overhead costs refer to costs related to assets (capital assets) acquired in one period and used over several successive periods of time and to costs not directly related to patient care but which are shared by many departments or units. Examples of overhead costs include building and equipment, general administration, cleaning, electricity, medical records, etc.

There are a number of reasons why measuring overhead costs is so contentious and difficult. In Australia, there are few standards of cost measurement for capital assets, either across States and Territories, across private and public sectors, across different institutional facilities. Public hospitals have usually chosen to exclude some types of capital costs and not others. There is very little consistency in the reporting mechanisms for these overhead costs. The costs of some types of assets are not reported at all in public hospitals. Private hospitals tend to include capital assets in their costs. Every pilot study site in Project Two reported widely different methods of accounting for overhead costs. This varied from separate cost centres for overheads encompassing some or all patient care cost centres, to separate overhead cost centres reporting separate overhead costs for each patient care unit. Some sites had very little idea of what exactly overhead costs were per patient in a specified ward and provided only a notional percentage of total costs as add-ons for overheads costs.

The method of depreciation of capital assets differs greatly from site to site. A number of sites used straight line depreciation whereby the costs of selected assets were allocated equally among all the periods from the time of acquisition to the end of their useful life. This is useful if the equipment requires little maintenance over the total period. Accelerated depreciation whereby the cost is depreciated most in the initial period of use makes more sense applied to equipment, for example, that loses its value much more quickly in the initial years of use. The cost estimate of equipment such as the bladder scanner also should take into account the life span of the equipment and how many patients it is used by.

Ideally, costing studies during the proposed field trials need to take these overhead costs into account and ensure that the reporting of these costs is provided in a standardised way across study sites. While the direct costs in the patient level costing studies give valuable information on costs of managing incontinence, accounting for overhead costs is important, particularly in economic evaluations of programs which compare outcomes and costs across different care settings. It is hoped that future costing studies will address these issues of overheads in more detail.

6.2.2 Description of Pilot Study Sites

6.2.2.1 Incontinence in the Acute Care Setting

St. George Hospital was the pilot site chosen to study cost and utilisation data for patients suffering incontinence in the acute setting. St. George Hospital is a 545-bed principal referral and teaching hospital. It provides acute tertiary health care in the South Eastern Sydney Area Health Service in New South Wales. In the financial year 1998-99, it had 46,500 separations of which 20 per cent comprised surgical cases. The average length of stay was 6.9 days and the cost per casemix-weighted inpatient (excluding intensive care and emergency departments) was $2,602 (Information Management and Clinical Systems Branch, NSW Department of Health, 2000). The hospital provides primary and community based services (172,430 occasions of service in 1998–99), as well as emergency and outpatient services (200,000 occasions of service in 1998–99). Eight surgical theatres operate fulltime. Numerous regional services are based here e.g. Cancer Care with radiotherapy facility, Regional Trauma Unit, Faciomaxillary Surgery, Liver Transplant, etc. It has 2,158 full-time equivalent staff and an acute inpatient expenditure of $130 million for the financial year 1998–99.

6.2.2.2 Outpatient Continence Care

The Pelvic Floor Unit of St. George Hospital has three Nurse Continence Advisors (NCAs) employed on a rotating part-time basis providing ward cover Monday to Friday for admitted patients who require management of continence conditions. In this pilot study, utilisation data was collected on 60 consecutive inpatients referred by the ward nursing staff to the NCA for the management of urinary and/or faecal incontinence (Substudy 2).

The Pelvic Floor Unit in St. George Hospital, opened in 1992, is devoted to the study and treatment of manages urinary and faecal incontinence. This multidisciplinary unit brings together an urogynaecologist, an urologist, and a colorectal surgeon, with specialist continence nurses working in all three disciplines, and is unique in Australia. The collaborative approach provides optimal interdisciplinary management of patients and research on all aspects of incontinence. About 4,800 patients per year attend the Unit which receives tertiary referrals from rural NSW, especially from the Wollongong and South Coast areas. Patients attending the Outpatient Department of the Pelvic Floor Unit were sampled as part of Substudy 3.

Information collected from each patient included: Patient name, medical record number, age, sex, date of admission and discharge, principal diagnosis and procedures, complications and co-morbidities, reason for referral to the NCA, initial assessment from the medical records, patient and caregiver history, physical examination, tests ordered or checked, management plan and interventions including patient education, institution of post-voiding test, voiding charts, pad usage charts and follow-up such as referral letters, appointments, instructions to ward staff and writing in the patient medical records.

In order to apply costs to the information collected on the services supplied by the NCA, each of the three NCAs was timed for two days by a project member to obtain an average time for the service items identified.

6.2.2.3 Incontinence in the Chronic Care Setting:

A. Port Kembla Hospital: patients with incontinence associated with neurological disease or injury

Data collection on the cost of illness was performed at Port Kembla Hospital in the Illawarra region of NSW for patients with neurological incontinence in a rehabilitation setting. Port Kembla Hospital is located in the Illawarra Area Health Service of metropolitan NSW. The Illawarra Area has a total population of 322,352 (ABS 1996) of which 13.8 per cent were aged over 65 years. The 1993 ABS Surveyof Disability, Ageing and Carers indicated that 18 per cent of the population considered itself disabled; 13 per cent of those under 65 years and 56 per cent of those over 65 years. Thus, in the Illawarra region, approximately 30,000 people less than 65 years and 18,000 over 65 years may need to access the service.

Port Kembla Hospital is part of the Illawarra Area Health Service Rehabilitation, Aged Care and Extended Care Service. Services are provided on an inpatient, outpatient or community basis including for the Aged and Disabled patient:

- Inpatient medical consultative services in rehabilitation and aged care assessment.
- Inpatient rehabilitation programs for patients with strokes, amputation, spinal damage, brain injury and chronic pain, as well as cardiopulmonary and orthopaedic programs.
- Outpatient clinics and domiciliary services for rehabilitation and aged care assessment.

- Comprehensive range of services by specialist rehabilitation nurses and allied health disciplines
- Nursing home and hostel liaison placement service.
- Day and inpatient respite services.
- Administration of the Program of Appliances for Disabled People (PADP), Rehabilitation Appliances Program (RAP) Scheme, Home Enteral Nutrition Scheme and Discharge and Palliative Care Oxygen.
- Care Support programs.
- A Specialised Brain Injury Outreach program.
- Psychogeriatric services to the community and residential care facilities.
- Occupational rehabilitation services.

Port Kembla Hospital accommodates Rees Ward, a 21-bed rehabilitation unit, and 2nd Floor Rehabilitation Ward, a 20-bed rehabilitation unit. Patients are admitted to Rees Ward for rehabilitation following strokes or myocardial infarction, while patients in the 2nd Floor Ward are predominantly amputees, and those admitted for general orthopaedic and neurological rehabilitation.

B. Sutherland Hospital and Community Health Service: the elderly and frail elderly

Sutherland Hospital and Community Health Service, located in the South East Sydney Area Health Service, is a major Sydney metropolitan acute hospital and community health service provider. The 287-bed hospital offers extensive inpatient and community-based services provided by 963 equivalent full-time staff to the Sutherland Shire's 200,000 residents.

In the year 1998–99, the Sutherland Hospital expended $49 million on acute inpatients. There were 21,660 separations, an average length of stay of 5.7 days, 19 per cent of which were surgical separations. It has an emergency department (28,738 occasions of service in 1998-99), six operating theatres, a large day surgery unit plus maternity, paediatric, psychiatric, general medicine and surgical wards (Information Management and Clinical Systems Branch, NSW Department of Health, 2000).

The Community Service consists of three Divisions: Southcare (Aged and Extended Care), Child Youth and Family, and Mental Health Services. Southcare is an integrated care agency whose purpose is to offer frail aged and younger people with disabilities, living in the Sutherland Shire, a range of services that will enable them to achieve optimal quality of life and function. Southcare is funded by Commonwealth, State and HACC and consists of: Geriatric Physicians, Generalist Community Nurses, The Rehabilitation Team, The Aged Care Assessment Team (ACAT), Dementia Outreach Services, and Associated HACC programs.

There were 22,504 people aged 65 years and over in the Sutherland Shire in 1996, representing 11.6 per cent of the total population. The population aged 65 years and over in the Sutherland Shire has increased from 7.8 per cent of the total population in 1981 to 11.6 per cent of the total in 1996, an 18 per cent increase overall (see Table 7 below).

Table 7 Increases in the aged population of the Sutherland Shire 1991 to 1996

Age group	1991 (persons)	1996 (persons)	% Percentage change
65–74	11 988	13 754	14.7
75–84	5 690	6 933	21.9
85+	1 391	1 817	30.6
Total – 65 years or more	19 069	22 504	18.0

Source: ABS Census 1996, Table T02, CDATA

The most significant growth in percentage terms has occurred in the 85 years and over age group, with an increase of 30 per cent. This significant increase in the "older old" (85+) requires attention, as this is the age group with the highest needs for support and other services. The rising number of the "younger old" age group (65–85) in the next 10 to 20 years will have has implications for future requirements for aged services in this area.

For many, an important aspect of ageing is financial security. However, the income distribution profile of older residents in the Sutherland Shire reveals that many are vulnerable. The percentage of all persons 15–64 years old who earn less than $200 a week ($10,400 per annum) was 25 per cent in this Shire, compared to 53.8 per cent for persons aged 65 and over. These numbers are consistent with the large numbers of older people in the Sutherland Shire relying on government pensions or benefits for their income.

Availability of residential accommodation plays an important role in housing for older people. In January 2000, Commonwealth Department of Health and Aged Care data showed that there were:

- 644 high-level care places in the Sutherland Shire, accommodated within 13 Nursing Homes, this is 27 places below the benchmark; and
- 502 low-level care places in the Sutherland Shire, accommodated within 9 Hostels, this is 336 places below the benchmark. The Commonwealth benchmark suggests that for every 1,000 persons aged 70 and over there should be provided 40 low care places. These figures show that Sutherland has only 29.94 places for every 1,000 persons aged 70 and over. There are only 20 designated dementia specific, low level places included within these figures.

John Paul Village in the Sutherland Shire opened in 1985. It consists of 166 self-care units, 75 hostel units and a 76-bed nursing home. The pilot studies for Project Two were conducted in the John Paul Nursing Home, which provides high level care with 74 beds available for long-term residents and 2 beds for respite care, and in the John Paul Hostel which has 73 beds for long-term residents and 2 beds for respite care providing both high and low levels of care.

Thomas Holt Memorial Village in the Sutherland Shire was established over 40 years ago, providing 85 self-care units, 77 hostel rooms and a 34-bed nursing home. Physiotherapy, podiatry, optometry, dental and diversional therapy are provided to the residents. Both the Nursing Home and Hostel were used as pilot study sites.

C. Incontinence in the Community Setting: Royal North Shore Hospital Aged Care and Rehabilitation Services

The pilot study on costs for the management of urinary and faecal incontinence in the community settings was undertaken at the Northern Sydney Area Health Service Aged Care and Rehabilitation Unit. The service, which began 12 years ago, is staffed by a fulltime Clinical Nurse Consultant (CNC) in continence and a part-time physiotherapist. The physiotherapist provides pelvic floor education programs and electrostimulation therapy. The CNC provides the following services through both clinic based consultations and home visits (including private residences, hostels, retirement villages and private hospitals within the Sydney north shore boundaries):

- Support and advice for people with indwelling catheters.
- Education on intermittent self catheterisation.
- Management of faecal incontinence and constipation.
- General education to nursing and allied health staff, and to the general public.

While the CNC in continence is attached to the Aged Care Assessment Team, the CNC also sees children with nocturnal enuresis and postnatal woman with continence problems. Referral to CNC services may be through self referral, the general practitioner, gynaecologist/urologist, community services or through the National Continence Helpline. There is no charge to the patient for this service.

6.3 Urinary Incontinence: Definition and Reported Prevalence

Urinary incontinence is defined by the Standardisation Committee of the International Continence Society (ICS) as the involuntary loss of urine which is objectively demonstrable and is a social or hygienic problem. The ICS does not state whether this "problem" is one perceived by the patient, perceived by their relatives/household members/carers, or perceived by the health professional asking the question.

The fact that "incontinence" requires the urine leakage to be a social or hygienic "problem" opens up another semantic difficulty. One of the target groups for Project Two is "men and women at risk of developing incontinence ". Therefore, studies in Project Two needs to consider the cost effectiveness of prevention strategies and/or early detection strategies for people who may well have had urinary leakage, but did not consider it to be a social or hygienic problem. Substudy 7 attempts to address the question of the hidden prevalence of incontinence by asking inpatients both whether they had a leakage problem of water or urine and whether they used pads of tissues to prevent wetness or soiling.

Estimates of prevalence vary partly due to a lack of standardised definitions of incontinence. This lack of consistent terminology has a direct impact when surveys are carried out asking people whether they have bladder or bowel leakage problems. Herzog (1990) reported that asking a probing question following a negative response resulted in an additional 10 per cent of subjects reporting incontinence.

The collection of data regarding the prevalence and incidence of incontinence is central to any cost of illness study of cost and utilisation of incontinence. Variations in the definition of incontinence can significantly alter the reported prevalence of incontinence and costs of treatment and care and thereby render inter-study comparisons invalid.

The definitions for urinary and faecal incontinence and the six case types were developed for this project after discussion with key stakeholders at the Stakeholders' Workshop on 29 October 2001 (see Appendix I). For the purposes of the studies in Project Two, urinary and faecal incontinence were defined uniformly across the study sites as the involuntary loss of urine or faeces on at least two or more occasions over two consecutive days.

While studies of the prevalence of urinary incontinence which have reported incontinence in community-dwelling women (Millard 1998) have been supported by more recent data from Women's Health Australia (Brown et al. 1998 & Chiarelli and Brown 1999), there are no Australian studies on the prevalence of incontinence in hospital inpatients. The prevalence of incontinence in patients whose principal diagnosis or procedure for admission is not directly related to incontinence is not known. The project therefore conducted a survey over one day at St. George Hospital of all inpatients to determine the prevalence of urinary and faecal incontinence and the use of pads. The method and results of this survey are provided in Substudy 7.

Section 7. Substudy 1: Patient Level Costing at Sutherland/Port Kembla Hospitals, Thomas Holt/John Paul Villages

7.1 Method

7.1.1 Study Preparation

The patient level costing involving the bottom-up collection of direct cost and utilisation data was piloted at four sites. The sites were the Sutherland Hospital (Rehabilitation and 4 East Wards), Port Kembla Hospital (Rees and 2nd Floor Rehabilitation Wards), John Paul Village Nursing Home and Hostel, and Thomas Holt Memorial Village Nursing Home and Hostel. The project was approved by the Ethics Committees of South Eastern Sydney Area Health Service, the University of Wollongong, and the University of New South Wales.

All pilot sites were offered the services of project team members to collect and coordinate the studies at each of the sites. Sutherland and Port Kembla Hospitals elected to utilize their own nursing staff, due to issues of privacy and familiarity with the staff routine and environment. The provision of site staff members rather than project team members differed between these two sites. The study preparation, in-service training and process of collection are provided in detail as these differences had significant implications for the conduct and outcomes of this project.

Two types of training services were offered at the study sites. The most resource intensive on-site training program was provided at the Sutherland Hospital. The program and the data collection at Sutherland Hospital were developed and coordinated by a team led by a fully trained Nurse Continence Consultant with research responsibilities. A full information package concerning the study objectives and data collection was developed by the project team in conjunction with the continence team over three days at the Sutherland Hospital (see Appendix C). Over a period of one day, a half hour in-service training was provided at staff handover time at each of the three shifts to nursing staff, physiotherapists and occupational therapists. The data collection form (termed the "Blue Sheet") was trialed and then revised over three iterations after feedback from the staff. The final version of the Sutherland Hospital data collection sheet called the Blue Sheet (see Appendix D) was subsequently used across all four sites in the chronic patient care setting.

No formal in-service training was provided at Port Kembla Hospital, John Paul Village Nursing Home and Hostel, and Thomas Holt Memorial Village Nursing Home and Hostel. At these five sites, there was an initial meeting with the medical and/or nursing staff to explain the purpose and conduct of the study. A project team member for each site provided instructions to the site data collector and managed the on-site data collection. At Port Kembla Hospital, an enrolled nurse from the hospital acted as data collector. Although a ward collection sheet was originally designed for use at Port Kembla Hospital, this was discarded in favour of the Blue Sheet from Sutherland Hospital because of ease in data entry and uniformity in data transfer and storage. The definitions of each element and the data entry process on the Blue Sheet were explained to the nursing staff, physiotherapists and occupational therapists at handover times over a period of three days in order to capture as many of the rotating ward staff as possible. At John Paul Village Nursing Home and Hostel, and Thomas Holt Memorial Village Nursing Home and Hostel, a project team member attended staff handover meetings to explain the data collection sheets to nursing and allied staff.

7.1.2 Data Collection

The data items on the Blue Sheet were developed by the project team in conjunction with the nursing staff at the pilot sites. The variables in the Blue Sheet were chosen as those that would be readily available and would meet the following criteria:

- Patient care measurement that is predictive of the cost of managing incontinence.
- Measurement would be reliable and valid.
- Items to be collected placed minimal demand upon the participating caregivers.

The selection and use of most of the data items were straightforward, such as the toileting assistance time, pad change time and bed change time. There were, however, a number of issues that arose

concerning some of the data items which led to a review of the sheet. For example, nursing staff requested provision in the Blue Sheet for recording a patient who was merely checked for incontinence and found to be dry. Staff also reported that linen changes should also take into account washing the patient as well as assistance requiring multiple staff members particularly for immobile patients. The Blue Sheet was trialed for one week at Sutherland Hospital before the final version was distributed to the study sites.

The commencement and completion dates for the pilot studies using the Blue Sheets varied across the sites depending on the availability of project members to coordinate and collect the data. These dates are shown in Table 8.

Table 8 Number of patients, commencement and completion dates of the pilot study sites

Site	Commencement Date	Completion Date	No. of patients
Sutherland Hospital	5 November 2001	23 December 2001	29
Port Kembla Hospital	29 October 2001	5 February 2002	24
John Paul Nursing Home	6 November 2001	13 November 2001	10
John Paul Hostel	9 November 2001	18 November 2001	9
Thomas Holt Nursing Home	10 November 2001	19 November 2001	10
Thomas Holt Hostel	7 November 2001	15 November 2001	7
Total			89

At Sutherland and Port Kembla Hospitals, daily log sheets were completed for consecutively admitted patients at each hospital with urinary or faecal incontinence for the duration of the patients' admission. For those patients whose length of stay was longer than 21 days, only the first 21 days were included in the study.

Due to the generally low levels of turnover and prolonged average lengths of stay in patients in the nursing homes and hostels, it was decided to recruit patients by collecting data from a nominated start date, including patients already admitted in these facilities and all subsequent admissions up to the end of the study. Daily log sheets were collected for a period of one week. The rationale for this more limited period of collection was that these patients were far more stable in their daily care requirements than those in the acute care setting and that the week's collection would be representative of the daily costs of caring for incontinence.

At John Paul and Thomas Holt Memorial Villages, patients were recruited using two methods. Nursing home patients in both Villages were selected retrospectively from the most recent 10 patients admitted from the commencement of data collection. This method of selection was chosen because of the relatively low turnover of patients and the limited period of collection for this project.

The original intention of patient selection in the hostel accommodation in John Paul and Thomas Holt Memorial Villages was to select retrospectively the most recent 10 patients admitted with incontinence. There were however, a number of exclusions and considerations in the selection of hostel residents.

- Hostel residents classified as eligible for nursing home admission (under category 2624) and awaiting nursing home placement were excluded because these hostel residents were for practical purposes nursing home-type patients. Approximately 6 out of the 150 residents fell into this category.
- Hostel residents who were not able to give informed consent were excluded.
- The nursing staff expressed the view that if all the selected residents resided in one particular area rather than another, it would be an unreasonable burden on the staff in that section. It was felt fairer to the staff to distribute the project work across the different hostel areas.
- Hostel residents who denied incontinence but whom the nursing staff regarded as incontinent were excluded because their inclusion was regarded as an invasion of privacy.

Therefore, the selection of residents resulted from consultation between the project data collector and on-site staff members who reviewed a list of all of the most recently admitted incontinent hostel residents for inclusion in the study. From this list, following the aforementioned exclusions, residents were selected. Substitutions, matched for age, sex and Activities of Daily Living (ADL) scores, were

made to ensure an even distribution through the various hostel areas. The selected hostel residents were then interviewed daily by the project member and their data collected on the Blue Sheets.

A summary sheet was completed for each individual outlining the reason for admission, basic demographic details and their principal medical conditions. A separate list was compiled recording the name of the patient with an assigned alphanumeric code designating the study site and unique patient identification number for that patient. All subsequent records of the patients were thereafter de-identified. A daily log of staff time and type and consumables was recorded on the Blue Sheets. These Blue Sheets were collected at the end of each day by the site data collector and replaced daily with a fresh Blue Sheet. These Blue Sheets were then collated and sent to the project data entry personnel.

One of the Project Team (J. Swinfield) attempted to administer the DBICI to all 10 of the hostel residents at one site but had some difficulty due to patients' dementia (see Appendix F).

7.1.3 Data Entry

The Blue Sheet is described in greater detail in the following section. Direct costs for the care of urinary, faecal and combined incontinence were collected under the two broad headings of staff costs and consumables directly attributable to continence care. Ward staff were requested to enter data on all staff time and consumables associated with incontinence care for the patients in the study. The Blue Sheet was designed to collect this information hourly for a 24 hour period. Data were entered for the hour on the assumption that no patient was treated twice by staff within an hour. Staff entered data on the length of time in minutes on each of the designated tasks, the number of staff involved and their designation and the number and type of consumables used.

Data were also disaggregated to reflect the staff and consumable costs incurred in treating faecal or urinary incontinence alone or in combination. It is important, however, to note that it was not possible to isolate the cost of an episode of urinary incontinence alone from one of combined urinary and faecal incontinence because the linen used in each circumstance may be the same. The cost of consumables however, for an isolated episode of faecal incontinence could be determined.

7.1.3.1 Staff Costs

Staff costs were obtained for full-time registered nurses, enrolled nurses, assistants in nursing, wardsmen, physiotherapists and occupational therapists. All were assumed to be aged over 18. The payment rates for staff differ across the sites in that staff at Sutherland and Port Kembla is paid according the New South Wales State Awards while the staff at John Paul and Thomas Holt Villages is paid according to Commonwealth Awards.

Advice was sought from business managers at each of the sites as to what a representative grade of staff in each category would be and it was decided that these would be a Year 8 registered nurse, a 5th Year enrolled nurse, 4th Year assistant in nursing, wardsman Year 1 (2nd Year), physiotherapist Grade 2 and occupational therapist Grade 1 (Year 2). These designations reflect the fact that most staff in each unit appear to be at or near the top pay scale of their respective category. These payments rates and staff designations were used as the basis for the calculations for staff costs in the four sites. These pay scales are shown in Table 9.

Table 9 Staff payment rates

Staff	Sutherland and Port Kembla Hospitals		John Paul and Thomas Holt Memorial Villages	
Grade	**Cost per Week $**	**Cost per Hour $**	**Cost per Week $**	**Cost per Hour $**
Registered Nurse (Grade 8)	870.50	22.91	853.40	22.46
Enrolled Nurse (Grade 5)	595.00	15.66	583.30	15.38
Assistant in Nursing (Grade 4)	488.90	12.87	479.30	12.51
Wardsman (Year 1, 2nd Year)	542.20	14.27	Not applicable	Not applicable
Physiotherapist (Grade 2)	972.51	25.60	Not applicable	Not applicable
Occupational Therapist (Grade 1 Year 2)	696.59	18.33	Not applicable	Not applicable

In addition to the base salary, on-costs were added to reflect provisions for annual leave, superannuation, and long service leave as well as worker's compensation cover. Add-on costs for members of nursing staff were 23 per cent, wardsmen 15 per cent and occupational therapists and physiotherapists 12 per cent respectively. Data were collected in this project on an hourly basis with the intention of adjusting costs according to the differential penalty rates depending on the shift the staff were on. It was not possible, however, to ensure accurate data collection over weekends and public holidays. It was also not possible to specify whether staff were employed on a casual or permanent basis and what the long service leave entitlements were. In order to determine whether in fact staff costs would be significantly different using the two methods of calculating staff costs: first, using specified shifts and associated differential penalty rates and second, using simplified aggregate on-costs, costs were calculated using the two methods and compared. This was performed using data for a seven day period for a patient from Sutherland Hospital who suffered from both urinary and faecal incontinence and whose management necessitated moderate to heavy levels of staff care. Over the seven day period, the average daily staff cost was $45.24 (range $34.68 – $71.86) using adjusted penalty rates compared to $50.80 (range $37.55–$89.77) using the estimated on-costs provided by the business managers at the sites. The difference in daily staff costs was between 5 and 6 per cent, with the greatest difference in the registered nurse category and least difference in the wardsmen category. It was decided for the purposes of this pilot study that estimated on-costs were sufficient to reflect staff costs associated with incontinence.

Data were abstracted from the Blue Sheets and entered into Excel (Microsoft Excel 2002, 1985–2001) spreadsheets called the Cost Master Sheets (see Appendix E). Data items on the Cost Master Sheets were formatted in parallel with the Blue Sheets. A workbook was allocated to each patient containing either 7 (John Paul and Thomas Holt Villages) or 21 (Sutherland and Port Kembla Hospitals) identical sheets, as well as a summary sheet, corresponding to the maximum length of stay in hospital. Within each Cost Master Sheet, data entry from the Blue Sheets was intentionally limited to time in minutes (toileting assistance time, bladder scan time, urinalysis/midstream urine time, rectal examination time, catheter and drainage system time and faecal incontinence time) and a limited range of values in the data items for pad change, bed change, 3 day flow chart and the number and designation of staff). Automatic adjustments were made to unit costs for staff time adjusted for staff designation, pad, catheter and drainage systems adjusted for type automatically by embedding auto calculation functions within the Excel spreadsheets in order to avoid accidental deletion or correction. Details on the values used for these embedded calculations are provided in Table 3, Table 4, Table 5 and Table 57. The data for each day was automatically summarised in a final sheet named "Cost Master Summary" for each patient.

This Cost Master Summary Sheet summarised average daily costs per patient (see Appendix E). The data items on this Cost Master Summary Sheet provided information about: Patient Identification Code, Medical Record Number, and Sex: male or female, Age in years, Patient subgroup (coded as (1 = frail elderly, 2 = dementia, 3 = neurological disease, 4 = elderly, 5 = none of the above), and length of stay in hospital in days.

7.1.3.2 Costs of Consumables

7.1.3.2.1 Pad costs

Pad costs varied between each institution and are summarised in Table 4. Patients in NSW public hospitals such as Sutherland and Port Kembla Hospitals receive continence pads from the institution at no cost to themselves. However, because this study has taken the societal perspective of costs, such costs have been taken into account since they represent costs to the society and the health care system. The price of pads in Sutherland and Port Kembla Hospitals, in common with all NSW public hospitals, is negotiated through a state-wide contract.

In John Paul and Thomas Holt Memorial Villages, approximately 40 per cent of patients appeared to obtain their pads through Program of Appliances for Disabled People (PADP) and this cost was recorded separately from the cost of other pads on a per patient/per institution basis. If a patient did not obtain pads through PADP then they may either have been provided with them by their institution or may have purchased them from the institution out of their own pocket. It was not possible in this study to ascertain how non-PADP pads were paid for. Costs for these non-PADP pads were estimated from the institutional supply costs.

Table 10 Continence pad costs

Pad Type	Cost $	Cost $
	Sutherland and Port Kembla Hospitals	John Paul and Thomas Holt Villages

Purple	0.10	0.35
Yellow	0.18	0.43
White	0.35	0.60
Blue	0.55	1.20
Net Pants	0.70	1.40

In addition to the consumables listed in Table 10, additional costs were incurred in waste disposal. These costs were generally uniform across the pilot sites and consisted of disposal costs of 96c per kilo for contaminated waste and 85c per kilo for general waste. Compactor charges for the collection of waste were $375 per month and tipping fees of $120 three times per week.

7.1.3.2.2 Bladder scans, mid-stream specimens of urine and rectal examinations

These items were not costed in the Cost Master Sheet, but their frequency of occurrence was noted per patient per day. As the bladder scanner was shared between wards within a unit, it was decided that a cost per scan would not be obtained but the cost to the unit would be ascertained by looking at the capital cost of the item as well as depreciation. The purchase price for a bladder scan is $7,000 and would be depreciated through the NSW Health Department accounting system by 20 per cent per annum over a period of five years. However, the attribution of the costs of the use of the bladder scan to individual patients is difficult given that this equipment is used for patients throughout the hospitals. MSSUs are submitted to several local laboratories and it is difficult to know which one an individual patient's was sent to. Costs per specimen were therefore not determined. Rectal examinations were not costed as the consumable materials used, namely, a small amount of KY Jelly and a disposable latex glove, cost so little. The method of accounting for and reporting overhead costs by substudy 1 sites differed substantially. The issue of just how overhead costs should be incorporated into costing studies is discussed in Section 9.

7.1.3.2.3 Catheters and Catheter Care

The catheter costs were similar in Sutherland and Port Kembla Hospitals but were more expensive in John Paul and Thomas Holt Memorial Villages as they were ordered individually instead of in bulk. These costs are summarised in Table 11.

Table 11 Costs of non-pad consumable items

Consumables	Cost $	Cost $
	Sutherland and Port Kembla Hospitals	John Paul and Thomas Holt Villages
Suprapubic catheter	4.50	13.95
2 litre urinary bag	0.59	2.85
Indwelling catheter	5.54	Not applicable
Urinary tube	1.35	Not applicable
"Flip flo" valve	3.68	Not applicable

7.1.3.2.4 Linen Costs

Linen costs varied between Sutherland and Port Kembla Hospitals due to local contractual arrangements with laundry services. These laundry costs are summarised in Table 12. Linen was laundered on-site in John Paul and Thomas Holt Memorial Villages, and it was not possible to determine costs per item for theses sites. It was therefore decided that these linen costs should reflect those incurred at Sutherland Hospital. Of the linen costs, the single largest would be that for changing "all linen" – the definition of "all linen" varied between institutions. The cost was thus altered by both the items used as well as their component costs.

Table 12 Linen costs

Linen Item	Cost $	Cost $
	Sutherland Hospital	Port Kembla Hospital
Bed blanket (cotton)	1.35	1.30
White bag general linen	0.61	0.41

Adult feeder	0.25	0.21
Gown short sleeve	0.67	0.49
Gown assorted colours short sleeve	0.30	0.24
Pillowcase	0.30	0.24
Pyjama bottom green summer	0.86	0.86
Pyjama top green summer	0.86	0.86
Sheet standard bed	0.99	0.95
Sheet draw	0.69	0.76
Sheet fitted	1.13	Not applicable
Towel bath white	0.35	0.35
Towel tea	0.28	0.27
Washer face cloth	0.15	0.31
Kylie pad	1.88	Not applicable
Full bed change	6.95	4.15

7.1.3.3 Assumptions and Default Values

To ensure uniformity of data entry at all the sites, a number of rules were developed to interpret and transfer the Blue Sheet data to the Cost Master Sheet. This section lists the key standard sets of definitions and rules developed by the project team responsible for the transfer of data from the Blue Sheets to the Cost Master Sheets.

- If the designation of staff member performing a task was not entered in the Blue Sheet, the default designation was enrolled nurse (all study sites).
- If more than one task was performed in an hour and more than one staff designation coded for this task, then it was not possible to say which individuals did which task. Calculations were therefore based on the assumption that all the staff who recorded for that hour were involved with all tasks in that hour.
- If variant activity (V) was recorded in the Blue Sheet, the back of the Blue Sheet was checked for an explanation for the entry. Together with collaborating information on the tasks performed for the patient, the incontinence was coded as faecal, urinary or both.
- An entry of "checked and dry" meant that no other task could have been performed during that hour.
- A maximum of two members of staff of the same type could perform tasks in a given hour, although there was no limit on the different types of staff designation involved.

7.2 Results: Chronic Care Setting

A total of 89 patients were included in the study. However, cost and utilisation data were analysed from only 65 patients, due to the exclusion of 24 patients from Port Kembla Hospital. Data collected from Port Kembla Hospital on 24 patients admitted with incontinence could not be analysed due to significant omissions and errors in the data from this site. Out of 228 Blue Sheets collected from Port Kembla Hospital, only 73 (32 per cent) were completed satisfactorily. No patient had a complete log of staff time and consumables. There were obvious omissions such as blank sheets interspersed with filled sheets pertaining to a patient requiring moderate to heavy levels of staff care for incontinence. Ticks were recorded instead of staff time in minutes. Pad types and linen were not recorded although their use was indicated with ticks. Staff designations were omitted. The enrolled nurse acting as the site data collector noted at the beginning of the study that incontinent patients fitting the study criteria were overlooked. This led to renewed efforts by the project team to encourage staff to identify such patients for the study. Despite this, incontinent patients were left out of the study. Fewer hospital admissions and low staffing levels over the Christmas and New Year period also hampered the collection of data.

In contrast, data collection at Sutherland Hospital was very methodical and reliable. There was consistency in the daily log data from patients requiring high levels of care. The Blue Sheets from Sutherland Hospital were accurately and completely filled leading to a high level of confidence with the accuracy of the staff time data.

In addition to the quantitative data collected at the hostel sites, the project team member reported on the case histories of some of the residents she visited whilst performing the DBICI. These case histories

(see Appendix F) provide a valuable insight into the self care and nursing management of continence conditions and the difficulties inherent in tracking the resource requirements for this patient subgroup. Unfortunately the DBICI could not be widely administered as patients found the income question too intrusive.

Of the remaining 65 patients in the study, 72 per cent were women. The average age of the patients was 83 years. There were 28 patients with dementia (43 per cent), 17 frail and elderly patients with incontinence (26 per cent), 15 patients with incontinence associated with neurological disease (23 per cent) and one young male admitted at Sutherland Hospital for a trial of void. As can be expected, the majority of patients with dementia were located in the nursing homes and hostels.

There were 50 patients with episodes of combined urinary and faecal incontinence. Twenty-five patients had episodes of faecal incontinence alone. Sixty-four patients had episodes of urinary incontinence alone.

Table 13 shows the gender, patient subgroup, average age and the average daily cost of subjects from the six pilot study sites. The average daily costs are disaggregated into total costs, staff costs and costs of consumables. The average daily costs are also reported according to whether the patients had urinary incontinence, faecal incontinence or combined urinary and faecal incontinence.

Average daily costs ranged from the highest ($67) at Ward 4 East in Sutherland Hospital which was over twice the cost in the two nursing homes and ten times the cost at John Paul Village Hostel ($5.56). Of these direct costs, on average, 82 to 86 per cent was attributable to staff costs compared to consumable costs. Consumable costs in relation to staff costs and study sites showed greater variability with respect to patients with purely faecal incontinence (range 0 to 31 per cent of total direct costs).

The collection of cost and utilisation data on an hourly basis allowed analysis of the distribution of costs across staff designations, daily shifts, and the types of consumables. As an example of the degree of detail this type of data allows, the figures from the daily log of 29 Sutherland Hospital patients are shown in Figure 1, Figure 2 and Figure 3 and Table 14.

The daily log of staff time showed that the median time spent on caring for any patient with incontinence was 109 minutes per day (inter-quartile range = 88–140 minutes). The distribution of the time spent caring for incontinent patients over a 24 hour period is shown in Figure 1. Although 45 per cent of the staff time caring for incontinence was in the morning shift from 7:00 a.m. to 3:00 p.m., a significant amount of time was also spent in the afternoon (25 per cent) and night (30 per cent) shifts.

Figure 1 Percentage of total staff time spent per shift

As shown in Figure 2, the type and designation of the staff involved in the care of incontinent patients were predominantly enrolled nurses (44 per cent) and registered nurses (39 per cent). Assistants in nursing and wardsmen contributed 7 and 8 per cent respectively with only one per cent each of the time contributed by occupational and physiotherapists.

Figure 2 Types of Staff Treating Incontinence

Staff spent a substantial proportion of time caring for an incontinent patient changing bed linen and in toilet assistance, as shown in Figure 3. What is even more interesting is that while staffing levels are usually lower in the night shifts, the proportion of total time spent in toilet assistance and bed changes remained high even during the night shifts. This is evident in Table 14. The tasks involving the staff were evenly distributed between toilet assistance, pad and bed changes and catheter care. Toilet assistance and bed changes required two or more staff members.

Table 13 Age, sex, patient subgroup and direct costs of continence care for Sutherland Hospital, John Paul Village Nursing Home and Hostel, Thomas Holt Memorial Village Nursing Home and Hostel

Site	Average Age	Sex	Patient subgroup	Total average daily costs $				Average daily cost of staff $				Average daily cost of consumables $			
				All	Urinary	Faecal	Both	All	Urinary	Faecal	Both	All	Urinary	Faecal	Both
John Paul Hostel	88	F = 8 M = 1	Dementia = 4 Neuro = 1 Frail elderly = 3 Elderly = 1	5.56	4.03	0.18	0.85	4.40	3.25	0.18	0.76	1.16	0.78	0	0.09
Thomas Holt Hostel	84	F = 6 M = 1	Dementia = 6 Elderly = 1	25.98	19.91	1.27	5.81	21.11	16.40	0.88	5.02	4.87	3.51	0.39	0.78
John Paul Nursing Home	83	F = 6 M = 4	Dementia = 5 Neuro = 4 Frail elderly = 1	23.21	16.70	1.24	3.25	19.28	13.95	1.15	2.78	3.93	2.75	0.09	0.47
Thomas Holt Nursing Home	81	F = 8 M = 2	Dementia = 5 Neuro = 4 Frail elderly = 1	34.36	17.92	5.07	8.90	27.35	14.06	3.89	6.94	7.01	3.87	1.18	1.97
Sutherland Killara Rehabilitation	79	F = 5 M = 5	Neuro = 3 Frail elderly = 5 Elderly = 1 Other = 1	42.85	29.76	3.79	5.20	37.23	25.85	3.48	4.22	5.62	3.92	0.30	0.98
Sutherland 4 East	87	F = 13 M = 6	Dementia = 8 Neuro = 3 Frail elderly = 7 Elderly = 1	67.24	41.18	5.92	16.69	54.74	32.85	5.03	13.90	12.50	8.33	0.89	2.79
TOTAL			65	49 (40.5-70)	34.8 (25.5-48.6)	3.9 (1-6)	6.7 (3.1-13.5)	41.3 (34.6-56.5)	30.4 (20/1-36.7)	3.1 (0.9-5.1)	5.2 (2.5-12.5)	7.5 (4.7-13.5)	5.2 (3.2-9.7)	0.7 (0.06-1.1)	1.2 (0.6-2.5)

* note that average costs for urinary plus faecal incontinence do not necessarily add up to total costs, because statistically, the average of one subset of the data plus the average of another subset of the data will not always add up to the average of the total data set.

Figure 3 Percentage of Total Nursing Time by Task

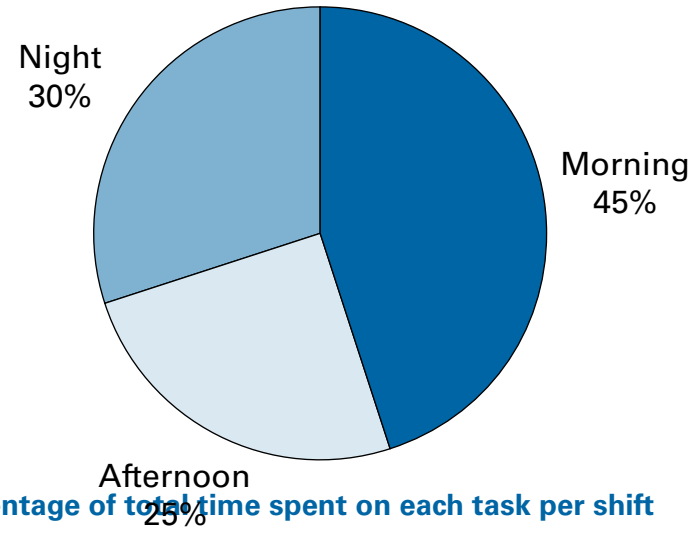
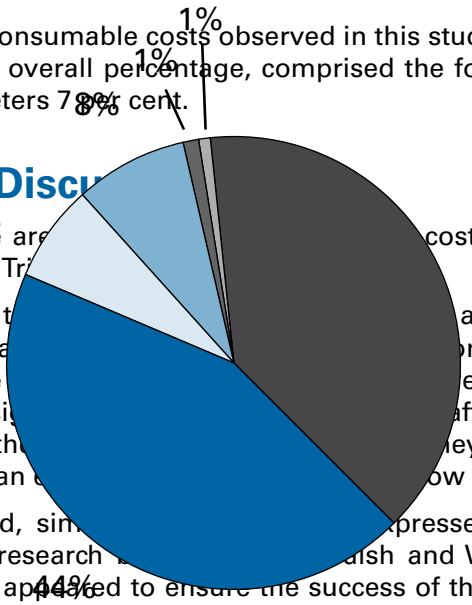


Table 14 Percentage of total time spent on each task per shift

	Morning Shift %	Afternoon Shift %	Night Shift %	TOTAL
Toilet Assistance	43	27	30	100
Pad Change	41	30	29	100
Bed Change	44	21	35	100
Catheter	38	36	26	100

The consumable costs observed in this study are shown on the far-right hand columns of Table 13, but as an overall percentage, comprised the following: Linen Change 69 per cent, Pads 24 per cent, and Catheters 7 per cent.



7.3 Discu

There are costing methodology in substudy 1 that can inform Project 3 (Field Tri

First, t at Port Kembla appear to arise from a relative lack of a "resea re importantly, the lack of a senior Nurse Continence Advisor at the el who had a defined research commitment at Port Kembla was si aff would welcome an extra pair of hands coming in to help with th ey definitely rejected this offer. As mentioned, they felt that such an ow their routine would be more burden than help.

Indeed, sim pressed at Sutherland Hospital but the presence of the CNCs with research alish and W. Prince) and the expert in-service training provided by them appeared to ensure the success of the project. At a feedback session, J. Walsh commented that during the first three weeks of data collection, staff needed constant positive reinforcement but then the "glitches" were ironed out. Future studies using this detailed bedside costing method must take account of this problem.

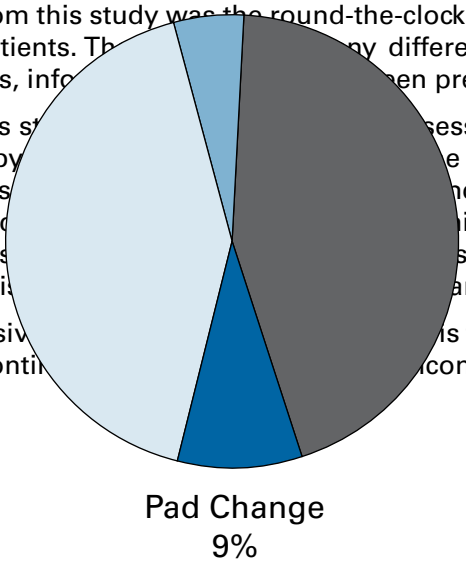
Second, the segregation between urinary and faecal incontinence was more difficult than expected. Of the 65 subjects, all but one patient had episodes of isolated urinary incontinence. 50 patients had episodes of mixed faecal and urinary incontinence and 25 patients had episodes of pure faecal incontinence. This is striking data and this was rather unexpected. The very high proportion with mixed faecal and urine leakage made it very hard to determine the real picture about the costs of faecal

incontinence in this setting. This may partly explain the complete dearth of publications on the cost of faecal incontinence in the nursing home mentioned in our First Report. One could conclude that once a patient has any faecal material on their bedclothes or sheets, with discolouration and malodour, then the clinical problem and its costing will have to fall under the umbrella of faecal incontinence.

The other striking finding from this study was the round-the-clock nature of the nursing time expended in caring for incontinent patients. Th ny differences in the time spent on morning, evening and night time shifts, info en previously reported.

The costs of undertaking this st sessed. It was difficult enough to ensure accurate recording of data by e staff to denote how much time they spent making the recordings nd unrealistic. Nevertheless, a total of 3,629 observations w ing that each recording took between 10 seconds and sixty seconds sts for acquiring these data were high. In order to undertake analysis an Excel database.

Despite the relatively expensiv s the only report published to date that gives a picture of faecal inconti continence, or in combination with it.



Section 8. Substudy 2: Patient Level Costing at St. George Hospital: The Nurse Continence Service "White Card" Study

8.1 Method

The Pelvic Floor Unit of St. George Hospital has three Nurse Continence Advisors (NCAs) employed on a rotating part-time basis providing ward cover Monday to Friday for admitted patients who require management of continence conditions. In this pilot study, utilisation data was collected on 80 consecutive inpatients referred by the ward nursing staff to the NCA for the management of urinary and/or faecal incontinence.

The inpatients seen and managed by the Nurse Continence Advisers were categorised according to their client group, including elderly, frail elderly, men and women at risk, women of child bearing age, people with dementia, and those with incontinence associated with neurological disease or injury.

Information collected from each patient name, medical record number, age, sex, date of admission and discharge, principal diagnosis and procedures, complications and co-morbidities, reason for referral to the NCA, initial assessment from the medical records, patient and caregiver history, physical examination, tests ordered or checked, management plan and interventions including patient education, institution of post-voiding test, voiding charts, pad usage charts and follow-up such as referral letters, appointments, instructions to ward staff and writing in the patient medical records. These data were recorded on White Index cards, which are held by the Nursing Continence Service.

In order to apply costs to the information collected on the services supplied by the NCA, each of the three NCAs was timed for two days by a project member to obtain an average time for the service items identified. Listed below are the tasks that were commonly rendered to the patients and which were timed. The listed service items spanned the entirety of the referral care from the initial assessment, follow-up visits and the discharge/referral management. Additional tests or interventions such as bladder scans and midstream/catheter urine specimens were also included in the cost estimations. It was assumed that when fluid balance charts were ordered by the NCA, that this was undertaken by a registered nurse and that this would occupy on average 2 hours. The staff costs were set at the hourly rates of $23.38 for the Nurse Continence Advisor (Clinical Nurse Specialist) and $22.91 for the Registered Nurse Grade 8 plus on-costs of 23 per cent.

Nurse Continence Advisor Task List

1. Initial Visit

- **Information gathering:** Review of patient's clinical notes, patient's bedside notes. Taking history from patient/carer, talking to nursing staff/the referrer, examining patient.
- **Assessment/Treatment Plan:** Define objective, order tests, instigate treatment regime.

2. Follow-up Visits

- **Assessment Plan Evaluation after initial visit:** Review of clinical notes, bedside notes, talking to nursing staff, checking results of initial MSU, performing trial of void.
- **Ongoing evaluation:** Review notes, discuss regime with patient/nursing staff.

3. Investigations/procedures

- **Check results and assess progress:** Reading clinical notes/talking to patient/nursing staff.
- **Give Product advice:** Review clinical notes, talk to patient/carer about available range of products, and choose products most suited to type of urine or faecal leakage. Arrange suppliers; educate patient, complete PADP/Para quad application form for subsidy depending upon eligibility.
- **Catheter management:** Insertion of catheter, educate patient and nurses about care of catheter, train patient in Clean Intermittent Self Catheterisation (CISC). Perform change of suprapubic catheter, arrange product advice, educate re supplies and suppliers, and ensure ongoing care by community nurse/general practitioner/nursing home staff.

4. Discharge Planning and Referrals

- **Discharge planning:** Referral to other agencies after discharge, arranging ongoing management, record in patient's clinical notes, discuss with patient/carer/nursing staff. Arrange suppliers; ensure PADP/Para quad applications carried out.
- **Referrals:** Type letter to agency/photocopy, or make telephone referral. Ensure patient and family are fully educated about goal of the referral and the benefit to be obtained.

The method of timing of the initial visits, follow-up visits, investigations and discharge planning is described below.

Timing of the Initial Visit

a. Reading patient's clinical notes

The time allocated to the initial consultation depended on the time taken to read the clinical notes, which in turn varied according to how long the patient had been in hospital. Thus, if the NCA was asked to see a patient admitted 1 or 2 days after admission, the NCA would only require a few minutes to read the clinical notes. Alternatively, the NCA would require a much longer period of time to read the more extensive records of a patient who had already been in hospital for a number of weeks. This could consume up to 30 minutes. Taking these factors into consideration, the time taken for this initial consultation in the ward ranged from five to 30 minutes.

b. Talking to the patient/carer/nursing staff/interpreter

The time recorded for this information gathering also varied due to a number of factors. For example, if the patient was non-English speaking, the NCA needed to wait in the ward until an interpreter could come and assist in the consultation. If a patient refused treatment, the NCA needed to return to the ward for another visit to that patient. Similarly, if the patient was absent from the ward, the NCA would have to return at another time. Finally, time (up to ten minutes) was spent finding and speaking to the staff caring for that patient and referring that patient.

c. Assessment/Treatment Plan/Completion of White Cards

The recording of patient information, assessment and treatment plan on the White Cards by the NCA took approximately five minutes. Overall, the tasks related to the initial consultation required 20 to 40 minutes.

Timing of the Follow-up Visits

Time taken to collect the clinical notes and read them ranged from five to fifteen minutes (average was ten minutes) depending on the patient notes, initial consultation and intervention. Ongoing evaluation included ten minutes to assess the progress of the patient and another ten minutes for treatment. Occasionally, additional time was needed for precautionary measures such as visiting patients under barrier nursing for Methicillin Resistant Staphylococcus infection. A considerable amount of time was spent by the NCA travelling within the hospital from ward to ward. The time taken to do this was extremely variable and not costed in this study.

Investigations

On average, the performance of a bladder scan by the NCA took 15 minutes. The process involved bringing the bladder scanner to the patient, reading the clinical notes, explaining the procedure to the patient, the scan itself and documentation of the findings in the White Cards. A fluid balance chart requested by the NCA and recorded by the ward nursing staff generally took one and a half hours by the ward nursing staff.

Discharge Planning

The time taken for discharge planning varied from five to 40 minutes. An uncomplicated case with no prior notification to the NCA of discharge took five minutes. However, if ongoing care/product supply and referral were required with agencies such as CRAGS, PADP and nursing homes, as well as patient education (for example, the routine care of catheters) the time for discharge planning consumed 30 minutes. Thus discharge planning took five to 30 minutes with referral tasks adding another ten minutes.

In addition to these tasks, patient management may also have required further telephone consultations. The NCA had to retrieve messages left on the answering machine, return phone calls, arrange appointments, photocopy and send out educational material or clinical notes for carers, provide product advice on continence products and liaise with other NCAs. These tasks are in addition to the

time logged during actual face-to-face patient contact and these costs related to inpatient continence care may be incurred even after the patient is discharged home.

Data Analysis

The times attached to the tasks listed were then assigned to the tasks recorded on the 80 White Cards used by the three NCAs. A project team member examined each of the White Cards in consultation with the NCAs assigning a time to the recorded tasks.

The cost per bladder scan of $2.90 was estimated by using the standard accounting practice of 20 per cent annual depreciation of the initial purchase price of $7,000 over a life span of five years, estimating average 10 scans per week, and 48 weeks per year. This resulted in an estimated cost of $2.90 per bladder scan. The cost of an MSSU was $20.10, from the charges raised by the hospital microbiology department.

8.2 Results

A total of 80 patients were referred to the three NCAs from 2 May 2001 to 12 February 2002 at St. George Hospital. The records for women of childbearing age were collected from 15 February 2000 to 27 July 2001 because this patient subgroup was under-represented in the former collection period. There were 32 were male and 48 female, with about 22 per cent each in the patient subgroups of frail elderly, elderly and patients with incontinence associated with neurological disease. There were smaller proportions of incontinent patients in women of childbearing age and patients with dementia.

Table 15 shows that the average cost of caring for an incontinent inpatient referred to the NCA ranged from approximately $40 (women of childbearing age) to $60 (patients with incontinence associated with neurological disease). The patient level data collected also enabled the analysis of the distribution of these costs amongst service items. Of the 100 bladder scans performed in this study, 55 per cent were in the elderly and frail elderly subgroup, 26 per cent in the patients with neurological disease and smaller proportions in those with dementia (14 per cent) and women of childbearing age (4 per cent).

Table 15 Sex, subgroup, mean age and staff time and consumables costs in patients referred to Nurse Continence Advisors

Subgroup (Total number)	Male	Female	Average age (years)	Average time (minutes)	Bladder scans (no.)	MSU/CSU (no.)	Fluid Balance Chart	Cost $
Neuro.(20)	12	8	79	123	26	13	1	59.45
Frail elderly (19)	7	12	86	119	33	17	0	57.52
Elderly (20)	7	13	83	108	23	11	1	52.20
Dementia (11)	6	5	85	105	14	6	0	50.75
Childbearing women (10)	0	10	33	82	4	4	0	39.63
Total (80)	32	48			100	51	2	

Since all patients received a first visit, the average number of visits ranged from 2.7-4.0, (standard deviation 1.2-2.7). The comparison of nursing costs versus total direct costs reveals that nursing time accounted for about two thirds of the costs in all cases.

The clinical outcomes were briefly categorised for this patient group, but are presented in the study of casemix coding, that features the same 80 patients (Second Report, Section 11.4.3).

8.3 Discussion

The NCAs providing the Nursing Continence Service at St. George Hospital were extremely busy and it was felt advisable not to burden them with prospective recording of their treatment times. The clinical shadowing of each nurse for two days by the research assistant (J. Swinfield) proved the most realistic way of determining an average cost for each of their tasks. The 80 patients seen were then costed using these times and costs.

The costing of consumables took a very simplistic approach. Only bladder scans and MSSU tests were recorded, as these were directly attributable to the Nursing Continence Service. In fact, many other consumables were used. But these consumables would have been taken from the ward supply, not from the budget of the nursing continence service. For example, the pads used to contain all incontinence for these subjects, the wet linen changed by the ward nurses, the time taken for linen changes by the ward staff etc. Having costed these methodically in Substudy 1, such costing was not repeated here, since the purpose of this pilot was to measure the operating costs of the Nursing Continence Service *per se*.

Patients with incontinence of neurological origin were generally the most expensive to manage. Assessment of these patients was the most time consuming, but they also required bladder scan to check post-void residual very frequently, as incomplete emptying is common in neurological patients. The assessment of the frail elderly was also time consuming and expensive, as their incontinence is often very multifactorial but sometimes may be completely reversible (i.e. if due to faecal impaction or urinary infection – both common scenarios). The women of childbearing age required the least time and consumables, as they often required simple pelvic floor exercise training. As mentioned previously, the 40-65 age group was not included in this substudy, as this group was not part of the Commonwealth specifications, in hindsight this was an important error.

The service is currently run by three NCAs each working an average of four days per week at a cost of approximately $29 per hour. Some of their time is spent training the registered nurses in continence management and catheter care, and each NCA also sees outpatients in the Pelvic Floor Unit afternoon clinic (see Section 9). Nevertheless, the service to ward patients would probably occupy 1.5 fulltime equivalent nurses. Considering the fact that the incontinence manifest by ward inpatients is very seldom coded during their AR-DRG assignment (this is discussed in Section 12.6 describing Substudy 5), this nursing continence service is not receiving appropriate reimbursement under the casemix-based funding system.

Nevertheless, the results of this substudy suggest that the method of "shadowing" NCAs to record their work practices, cost each typical activity, calculate costs for dedicated consumables, then produce a cost of care episode for each pilot group did yield useful information that was relatively cheap to acquire.

The average cost per patient for the Nursing Continence Service ranged from $39-$59. It is not known what percentage of inpatients at St. George Hospital is seen by the Service. The demand for their service increases annually. This is despite the fact that the Continence Nurses undertake regular educational workshops for general nurses in all wards about continence management, so that simple tasks such as catheter care can be performed by ward staff. Regardless of such in service training, demand for their service is increasing, presumably because hospital inpatients are increasingly frail and elderly, as the demographics of our population becomes more "aged".

Section 9. Substudy 3: Patient Level Costing at St. George Hospital – The Costs of Outpatient Care for Urinary and Faecal Incontinence at The Pelvic Floor Unit

9.1 Introduction

So far in Project Two, the majority of pilot studies have concerned inpatient care. In Substudy 3, the staff and consumable costs for the investigation and treatment of patients with urinary and faecal incontinence in an outpatient clinic at St. George Hospital were recorded for one week. No attempt was made to measure overhead costs, but these are considered in the Discussion. As the Pelvic Floor Unit (PFU) is not only a treatment centre but also a research unit, the costs for many visits include costs associated with research activities. These are included because, had these research activities not been undertaken, the same amount of staff time would have been spent in routine clinical care. The Director of the Unit (K.H. Moore) is a full time clinical academic, but might just as well have been a Staff Specialist in which case research activity would have been a lower priority.

9.2 Patients and Methods

It should be pointed out that although the PFU is located within an acute care hospital, the patients attending it during this study were all ambulatory community-dwelling patients, who are all mentally intact (not suffering from appreciable dementia). Because they attended the Unit by their own transport (or in a few cases, by volunteer Community Transport) and all reside either at home or occasionally in an independent Hostel, they were not Frail Elderly.

There are four "portals of entry" to the PFU. The most common means of access is via general practitioner referral to K. Moore, for urogynaecology management. These patients are women with a median age of 55 (Prashar, Moore et al. 1998). Thus over a third of the patients are women of childbearing age. At least two thirds of these patients are age less than 65, so are not in the Elderly category.

The second most common entry point is via self referral to the Nurse Continence Advisors, who see patients five afternoons per week in the PFU. These may be men or women who seek continence management. Also, patients who have seen the NCA on the ward as inpatients attend the PFU for subsequent treatment.

The third most common entry point is via referral from the PFU colorectal surgeon, who sends patients to his research fellow in the unit, for investigation of faecal incontinence, or for biofeedback therapy in the management of disorders of defecation. Their first visit is carried out in the colorectal surgeon's office, as he is a Visiting Medical Officer at St. George Hospital, not a full time academic.

The fourth entry point is via referral from the PFU urologist, who performs urodynamics testing in the X-ray department in conjunction with the PFU urodynamics NCA. Their first visit also occurs in the urologist's office, as he is also a Visiting Medical Officer. As these patients do not enter the physical building of the PFU, they are not included in this pilot study. Such patients are commonly men with incontinence of neurological origin, or incontinence associated with outflow obstruction.

The nature of the referral source/patient type will be evident in this pilot study, but within the time constraints of the study, it was not possible to measure the detailed demographic features of the patients in the sample. The focus of this pilot sample was measurement of investigation/treatment costs.

The types of clinical activities are briefly described, along with an overview of the way in which staff time and consumables were expended during these activities. A logical sequence of first visits, investigation visits, then follow up visits, is pursued.

At a typical first visit for urinary incontinence, the patient's basic history is taken by a one of the two PFU research nurses (cost $25.00 per hour), then the history is further clarified by a registrar ($28.00 per hour), a urogynaecology research fellow ($25.00 per hour), or the consultant ($155.00 per hour). The doctor also examines the patient (consumables comprise speculum 72c; gloves 88c, linen laundry charge $1.26, blue disposable mini draw sheet 11c). A midstream urine culture is sent ($20.10). Treatment is commenced, which may involve a prescription ($3.50). Explanatory literature is given (photocopied

by the Unit staff, costed nominally at $1.00) and a video tape may be loaned (costed at $2.00 because these videos have a limited life span, costed for replacement of tape and time to make copies).

If presenting symptoms include incomplete emptying or voiding difficulty, a uroflowmetry may be performed. In lieu of any reasonable measure to calculate the depreciation cost of the uroflow machine ($8,000), $18.55 is taken as the Medicare rebate for this procedure. The lifespan of the equipment and number of uroflow tests per annum is unknown thus making any estimate difficult. The post void residual urine volume is measured by a bladder scan. The cost for this derived from cost of purchase ($7,000) depreciated over 5 years ($1400 per annum) divided by 48 working weeks per year ($29.15 per week) divided by an average of 10 bladder scans per week from the present data ($2.90 per scan). There is no Medicare rebate item for this procedure that can be used as a surrogate measure of cost.

After the first visit, patients are generally booked for a cystometry test or a video urodynamics test in the X-ray department, although if leakage is mild and symptoms are not complex, they may be commenced on a conservative therapy regime without further testing. The cystometry test involves clean prep of the vulva and urethra (small dressings pack 53c, saline sachet $2.23, gloves 88c) catheterisation with a manometry line and a fluid fill line and a rectal balloon is placed ($3.74). Total consumables for cystometry costed at $28.55. If video urodynamics is undertaken, costs are as above with the addition of X-ray contrast material urograffin ($26.70 per test). Each test takes 30-45 minutes and requires one urodynamics nurse and one registrar or consultant (staff costs were tallied).

At follow-up visits, similar activities that occurred at the first visit occur in varying combinations, such as prescriptions, uroflow and residual bladder scan and additional literature. Other events may occur that could not be costed within this simple pilot study, such as referral to an outside physiotherapist for electrical stimulation of the pelvic floor, or preparation for surgery (involving chest X-ray, ECG, full blood count). Also, booking of a patient for surgery may occur at these follow up visits but the cost implications of such events could not be calculated within this simple pilot study.

Some follow-up visits involved fitting or changing the bladder neck support device, a ring pessary with urethral supports that may be fitted by the nurse continence advisor or by the medical staff. The cost of this device is $175 for a lifespan of 3 years with the additional cost of sterilisation of 72c. The device is discarded if it appears discoloured, duration of this event is not known. This device is not widely used as it is considered a research tool at present. A further "research event" comprised of follow-up visits for the electromagnetic chair, a treatment for detrusor instability. Only staff costs were recorded for this follow up visit, because it is a research tool.

Additional follow-up visits were conducted solely by the NCAs who staff the Nursing Continence Service (referred to in Section 7). These were not costed separately. Further treatments provided solely by the NCA were change of suprapubic catheter, and teaching clean intermittent self-catheterisation. The cost of the new suprapubic catheter and the use of disposables were costed.

Patients with faecal incontinence are seen by the colorectal research fellow ($25.00 per hour), largely for the purpose of undergoing anorectal manometry testing. This was costed on the basis of time spent and consumables used.

At the commencement of the PFU study, an attempt was made to administer the Dowell Bryant Incontinence Cost Index (DBICI) to a consecutive series of women seen at the Unit. This proved to be simply unworkable, as each DBICI questionnaire requires 20 minutes for completion, and could not be accommodated within the heavy workload of the Unit.

Within all of the visits, the time that the patient spent with the clerical officer, booking the next appointment, explaining various tests etc, was also recorded and costed.

9.3 Results

Table 16 Median and mean costs of incontinence management in outpatient setting

Type of Visit	No. of visits	Median	Interquartile range	Mean	Standard deviation
First visit	9	40.51	25.05-100.60	65.83	61.80
Urodynamics	6	93.24	80.36-130.18	105.27	50.18
Cystometry	3	89.45	45.20-97.50	77.38	28.16
Follow-up	37	11.85	7.65-30.73	24.55	25.31

Electro chair	12	10.25	8.03-13.38	9.59	3.79
Other research	8	15.21	5.76-25.36	15.45	9.91
Suprapubic change	3	101.29	14.06-103.69	73.01	89.66
CISC training	2	12.37	9.92-14.83	12.37	3.47
Anorectal test	9	23.28	18.35-37.57	24.17	9.20

The overall cost for these 92 occasions of service was a median of $17.51, inter-quartile range of 10.60 – 49.66. However, the data were quite skewed by the larger number of cheaper follow up visits. The week chosen was the "off fortnight" in which 3 cystometry tests are seen on the Monday. In the alternate week, 6 new patients would have been seen. Therefore the mean cost was also calculated, at $37.97, standard deviation $44.23.

If these 92 occasions of service in the PFU are multiplied by the 48 full working weeks in the year, (= 4,416 occasions of service per annum), then the annual cost would be $167,675.52 per annum using the mean figure, and $77, 324.16 per annum using the median cost. Since the annual budget for the Unit is much closer to $167,000 per annum, the mean figures appear to be a better representation.

9.4 Discussion

The overhead cost of the Pelvic Floor Unit was not included. For example, the two clerical staff that provide support to the unit are essential to running the facility but their salaries were not included, except for the time spent in helping each of the 92 patients. Overhead costs of heating, lighting, cleaning were not included.

The most important point to emerge from this study was that the most common type of patient who visited the PFU during this pilot study, i.e. a woman aged 40-65, is not included within the brief of the Tender for this project. This was not realised until the study was concluded and the data were being entered. However, the Chief Investigator, K. Moore, indicated that in the 11 years since the PFU opened the vast majority of our patients fall into this age bracket. None of the patients have appreciable dementia, since patients with dementia are referred to the NCA at CRAGS (Community Rehabilitation and Geriatric Service). The same is true for the Frail Elderly. Also, patients with neurological incontinence are generally referred to the urologist because this is Unit policy. Of course, with a median age of 55 years, many women of childbearing age are seen, as are ambulatory Elderly patients. Nevertheless, there is a huge demand for our services; the average waiting time for a new appointment (first visit to K. Moore urogynaecology service) is 14 weeks.

The second point to mention is that although the PFU has a strong focus upon the outcome of treatment, these could not be assessed within one week, and were beyond the scope of this Project. Since the pilot studies were undertaken, the Outcomes Project has recommended a suite of outcome measures (Thomas et al. 2004) so that cost-effectiveness analysis could be readily undertaken in this Unit.

The third point of interest arising from our data is the difference in cost for the urogynaecologist patients and the NCA patients. The first visits for urogynaecologist patients were generally quite expensive ($100), because these are often quite complex patients, and are allocated 45 minutes, but can take up to one hour. The history is often taken by one of the research NCAs, and then the patient is seen by a registrar/fellow/consultant, which is quite expensive. The first visit for NCA was much cheaper ($30): they are allocated 45 minutes, and are generally managed within this time.

On the other hand, follow up visits by the urogynaecologist (K. Moore) are only allocated 15 minutes and are usually only seen by one clinician. NCA follow up visits can be quite extensive, such as training in clean intermittent self catheterisation, change of supra pubic catheter, and often take a further 30 minutes or more.

An important point, regarding future FieldTrials, relates to the DBICI. It was unfortunate that a consecutive series of these could not be administered to our sample, although the results of the DBICI in 100 such women have already been published (Dowell et al. 1999). The DBICI measures the patient's personal ("out of pocket" costs for pads etc.) and treatment (both Medicare and out of pocket costs) expenditure. This Index measures costs from the patient's perspective, whereas the current substudy has measured the costs expended within the hospital budget for investigation and treatment of incontinence. Obviously the field trials (Project Three) will need to consider costs from both perspectives. Administration of the DBICI would need to be performed by a separately funded project team member.

Finally, the study of outpatient management was unfortunately confined to one week in the outpatient setting. Obviously, some of the patients encountered here will eventually require surgery, but no surgical costs have been captured anywhere in the whole of this Project (although Casemix data for patients with urinary incontinence is considered in Substudy 5, Section 11, and found to give little information). The lack of information about the surgical costs for urinary incontinence and faecal incontinence is a major shortcoming of the present Project. In retrospect, it has largely arisen from the fact that the Tender specifications excluded patients from above childbearing age (i.e. 40+) to below "elderly age" (i.e. <65 years). In women, the age group most likely request and be suitable for surgery are those who have completed their family but are well enough to tolerate anaesthesia, i.e. age 40-65. This age group warrants full consideration in any proposed field trials.

Section 10. Substudy 4: Dowell Bryant Incontinence Cost Index (DBICI) in Community Dwelling Elderly

10.1 Method

Collection of the data for this study was undertaken by the Nurse Continence Consultant (NCC), Caroline Dowell, who was one of the original authors of the Dowell Bryant Incontinence Cost Index (Dowell et al. 1999). Dowell, who is attached to the Northern Sydney Area Health Service Continence Service, commenced data collection on 17 August and ended on 15 December 2001. A total of 13 subjects were included in the study. The subjects were consecutive clients with a urinary and/or faecal continence problem referred to the continence clinic at Royal North Shore Hospital. All clients requested a home visit. Clients with catheter care needs or transient incontinence were excluded from the study. It should be noted that there are no facilities at Royal North Shore Hospital for the NCC to see these patients on an outpatient clinic basis. The project was approved by the Ethics Committees of Northern Sydney Area Health Service and the University of New South Wales.

On the initial home visit, each client completed a consent form. The NCC completed demographic data, the Dowell Bryant Incontinence Cost Index, the St. George Score and recorded the length of visit and travel time taken. The St. George score is a 20-point score containing four categories: stress leakage (0-4), urge leakage (0-4), use of pads (0-8) and impact on quality of life (0-4). The higher the score the greater is the severity of incontinence. This data was collected in addition to the NCC's usual minimum data set recording and full continence assessment. On subsequent visits travel and visit time was recorded, in addition to the cost of any interventions. The collection sheets used in Substudy 4 are shown below.

Table 17 Community-Dwelling Continence Log Sheet

GENDER	
AGE	
HOUSING	
INCOME SOURCE	
SYMPTOMS	
NO PADS/24	
TYPE OF PAD	
CAAS/PADP/REPAT	
REASON FOR HV	
ST G SCORE	
DBICI 12/12	
RESPONDER	
TRAVEL TIME	
TRAVEL COST	
CONSULT TIME	
ADMIN COST	
INTERVENTION COST	
RECOMMENDATION COSTS	

INCOME SOURCE

1. Invalid pension
2. Aged pension
3. Repat
4. Carers pension
5. Special benefits
6. Other pension
11. Superannuation
12. Overseas pension
16. Other non-government income

HOUSING

1. Own/purchasing
2. public/rental
3. private rental
4. forces
5. boarding house
6. hostel
7. nursing home
8. other

SYMPTOMS

1. urgency
2. frequency
3. stress leak
4. urge leak
5. mixed
6. insensible
7. nocturnal enuresis
8. incomplete emptying
9. POP
10. chronic cystitis
11. nocturia
12. pain
13. voiding dysfunction
14. catheter care
15. functional incontinence

TYPE OF PADS

1. liner
2. light
3. moderate
4. heavy
5. all-in-one
6. pouch
7. sheath et al.
8. catheter
9. DIY e.g. tissues, old bed sheets

PROVISION OF PADS

1. Self funded
2. Repat
3. PADP
4. CAAS

INTERVIEWEE

1. Patient
2. Spouse
3. Relative as carer
4. Paid carer

Table 18 St. George Urinary Incontinence Score

Name/No _____

Date _____

Incontinence	Never (0)	Rarely (1/d-1 wk)	Sometimes (1/day)	Often (2/day)	Always (3+/day)
Stress	0	1	2	3	4
Urge	0	1	2	3	4
Pads – damp	0	1	2	3	4
– soaked	0	2	4	6	8
Lifestyle	0	1	2	3	4

Total/20

10.2 Results

The results of the cost survey in the 13 community dwelling clients seen by the NCC are summarised in Table 19.

Table 19 Age, sex, Dowell-Bryant Incontinence Cost Index, travel and consultation times and reason for home visit by Nurse Continence Consultant

No	Age	Sex	DBICI 12 months $	St. George Score	Travel time (all visits)	Consultation time (all visits + admin time)	Reason for Home visit	Symptoms
1.	88	F	1252.68	13	60 mins	105 mins	Mobility	5,6
2.	79	F	2695.16	16	40 mins	70 mins	Mobility	1, 8
3.	81	F	585.00	12	60 mins	60 mins	Mobility	1,4
4.	92	F	1391.52	12	240mins	155 mins	Mobility	1
5.	81	F	36.40	8	60 mins	105 mins	Mobility	5
6.	71	M	645.00	9	40 mins	65 mins	Parkinson's disease	1,4
7.	85	F	5460.00	–	90 mins	105 mins	Mobility/ transport	8,9
8.	46	F	6943.50	20	20 mins	80 mins	Mobility/ cognitive	10
9.	93	F	2435.16	16	60 mins	50 mins	Mobility	8
10.	72	M	924.00	7	80 mins	70 mins	Mobility/ MND	7
11.	90	F	3129.00	11	40 mins	80 mins	Mobility	5
12.	65	F	327.00	8	60 mins	120 mins	Anxiety	1,4
13.	80	M	1638.00	10	100 mins	120 mins	Mobility	7,8

The study contained 10 women and three men with an average age of 80 years. The reasons for the home visit generally were lack of mobility or transport and in two cases, debilitating neurological conditions. The total time required for the home visits and associated administrative tasks ranged from 1 hour and 45 minutes up to over six and a half hours. The DBICI over a 12 month period ranged from approximately $36 to over $6000.

The total expenditure for personal care costs over 7 days and multiplied by 52 weeks, plus the total treatment costs over 12 months, revealed very high figures per annum. This is not surprising considering the severity of their St. George scores. Many of the patients scored over 12/20 on the St. George test, indicating that they had frequent and socially debilitating leakage with regular use of pads. Only 1 of the 13 subjects had faecal incontinence.

The sample size contained in this pilot was smaller than the target sample size of 20, largely because patients often refused to be involved in the 20-30 minute interview required. Since these interviews were part of a home visit, the researcher was not in a position to "push the point" and body language (e.g. standing near the door) was sometimes used to indicate that further discussion of the DBICI was fruitless. There were difficulties in the data collection in Substudy 4 especially when patients were requested to volunteer their disposable income. Many patients were unwilling to divulge such information and in many cases it was obvious from the surrounds of the patients that their incomes were possibly greater than that volunteered. Whilst there were limited numbers of patients recruited in this substudy, the data collected were detailed and accurate.

The types of patients varied widely. Four examples are given:

1. A 92 year old lady, who was completely housebound by her incontinence, complained of severe urgency and frequency with urge incontinence over many months. Routine midstream urine culture revealed severe bacterial cystitis. She was given three courses of antibiotics (NCA liaised with the GP) and thereafter became completely continent.

2. An 88 year old lady with severe constant leakage had grossly excoriated vulva and thighs from urine soaking over many months. She was using bath towels for containment and soaking the

bed at night. The NCA found that she was drinking 3-4 litres per day, and was on a high dose of lithium (blood levels far above therapeutic: NCA asked the general practitioner to test the levels), which provokes thirst. Her dose was reduced, her fluid intake declined, and her leakage markedly improved. She was fitted with Dependa button-top pads, containing absorbent gel, so the urine excoriation ceased and she became socially continent.

3. A 79 year old lady with moderate dementia living in a hostel was referred for assessment of nursing home placement because her incontinence could not be managed by hostel staff. She was cutting up garbage bags to put on the bed at night, to protect the mattress from urine spillage, and using cut up sheets for containment. She was fitted with Tena "Huggie" pull up pants, containing absorbent gel, which she could pull down quickly in the toilet. As these were too expensive for her to afford, she was placed on the PADP scheme for pad provision. This provided her with social continence, and nursing home placement was not required.

4. A 46 year old depressed woman had tried to commit suicide by jumping off a train, resulting in a fractured pelvis and trauma to the urethra with continual incontinence. She was also on high dose lithium. She was using five child nappies per day fully soaked, and had excoriation. She was given appropriate containment pads and rendered socially continent.

None of these patients had actually received any prior treatment; so that the DBICI results represented their personal costs for pads, linen, laundry, and over the counter skin ointments to relieve excoriation from urine soaking.

The Northern Sydney Area Health Service Aged Care and Rehabilitation Unit do not offer a clinical room for outpatients. Other Aged Care and Rehabilitation Units offer this option and it may be better to choose such sites in future.

10.3 Discussion

Although the number of patients who were prepared to undertake the DBICI was small (because of their reluctance to divulge information about their type of income), this substudy provides the most compelling evidence of the economic "burden of disease" of any of the pilot studies.

The reason is that this substudy captured mainly frail elderly patients who were living at home, without professional carers, but who suffered an enormous burden of disease. This substudy bears out the recommendation of the Standardization Subcommittee of the International Continence Society, that personal cost data provides a separate measure of the severity of the condition.

Section 11. Substudy 5: Casemix Analysis of Urinary and Faecal Incontinence in the Acute Setting

11.1 Pilot samples of review of casemix coding for urinary and faecal incontinence conditions in the acute care setting

The purpose of this pilot study was to determine whether casemix coding is sufficiently precise to determine whether the co-morbidity of incontinence or urinary retention increases the cost weight or the length of stay of the primary disease code in cases such as acute stroke, surgical, general medical and obstetric/gynaecological conditions. The pilot study was undertaken in four parts.

In Part One, a series of hypothetical patients were created who had a non-incontinence condition as their primary disease. The effect of adding urinary or faecal incontinence to their casemix coding was assessed to see whether it increased their Cost Weight or average length of stay.

In Part Two, a consecutive series of "real" patients who had a primary diagnosis of a non-incontinence condition over one month at St. George Hospital were examined. The patient's Cost Weight and LOS were printed out then the DRG of "incontinence" was subtracted from their diagnoses, to see if any change in the Cost Weight or LOS occurred after this subtraction.

In Part Three, a consecutive series of patients with a Primary Disease Code of incontinence at St. George Hospital was obtained from the Clinical Coding Department, to see whether the number of patients with this primary diagnosis was accurate.

In Part Four, the same 80 patients who had been attended by a Nurse Continence Advisor at St. George Hospital (with costing of NCA care) were studied after discharge, to determine whether their co-morbidity of incontinence had been accurately coded within the casemix classification system at the hospital.

11.1.1 Methods for Part One

The investigator (K. Moore) consulted with the head of the Clinical Information Department at St. George Hospital, to discuss coding of incontinence using Australian Refined Diagnosis Related Groups (AR-DRGs) with the input of four clinical coders. The specific codes for any incontinence were:

N39.3 Stress incontinence

N39.4 Other specified urinary incontinence

R32 Unspecified urinary incontinence

R15 Faecal incontinence (see 11.1.3 for results)

A series of hypothetical typical patients were then constructed using the casemix coding software, and their AR-DRG Version 4.1 cost weights and lengths of stay (LOS) were ascertained for the principal diagnoses alone and then again with the secondary diagnosis of incontinence. Differences in cost weights and LOS were then assessed.

The Clinical Information staff pointed out that the Patient Clinical Complexity Level (PCCL) might also alter with respect to incontinence. This item is not contained on the routine software printout so the clinical coders and the investigator obtained this from the software and recorded it manually in certain cases (although this was more time consuming). The PCCL is a measure of the cumulative effect of a patient's complications and co-morbidities, and is calculated for each episode of care. The calculation is complex and has been designed to prevent similar conditions from being counted more than once. The PCCL ranges from zero (no complication and co-morbidity effect), to 1 (minor effect), 2 (moderate), 3 (severe) and 4 (catastrophic).

Sample modelling exercises

Based on the investigator's clinical experience with Acute Care setting of St. George Hospital, eleven common scenarios for urinary or faecal incontinence were described. The cost weights and LOS were calculated with and without incontinence. In some cases, urinary retention and insertion of a suprapubic catheter were also added as secondary diagnoses, to see whether these conditions/procedures would increase the cost weight or the LOS, or affect the PCCL. The rationale for this was that urinary retention, left untreated, leads to overflow incontinence. This clinical sequence is a common postoperative event. Next, eleven clinical scenarios were constructed for faecal incontinence, and then faecal impaction was added in some cases. These comprised nine of the same clinical conditions used in the urinary

incontinence settings and two new clinical scenarios. In each case, faecal incontinence was subtracted from the equation and the Cost Weight/LOS was reassessed.

11.1.2 Results for Part One – Urinary Incontinence

Example 1

A hypothetical 65 year old female with dementia (B63zZ) had AR-DRG cost weight of 2.45, LOS 13.95 days, PCCL 0. When R32 unspecified incontinence was added: the cost weight and the LOS did not change but PCCL became 2. When R33 retention of urine was added, the cost weight and LOS did not change but PCCL increased to 3. Percutaneous suprapubic cystotomy drain 3701100 was added with no changes in cost weight, LOS or PCCL. Hence incontinence, retention and suprapubic catheter had no effect on the cost weight or LOS in this patient with dementia.

Example 2

A 50 year old female with uncomplicated stroke (B70cC) had a cost weight of 1.48 and LOS of 6.82 days. Unspecified incontinence R32 was added: the cost weight increased to 3.94 and the LOS to 17.79 days. If the stroke was then complicated by hemiplegia (changing the AR-DRG to B70aA), the cost weight and LOS remained unchanged. Therefore, the effect of incontinence was somewhat masked if she had a complicated stroke. However, if the incontinence was then removed, leaving only the complicated stroke, the cost weight decreased to 2.1 and the LOS to 10.15 days. Thus the incontinence with stroke complicated by hemiplegia did have some effect on resource utilisation and cost.

Example 3

An 85 year old male with fractured femur after a fall in hospital requires general anaesthesia for open reduction and internal fixation and thus is grouped into 108bB which has a cost weight of 2.94, LOS of 9.23 days and PCCL of 0. If R32 incontinence was added, the cost weight and LOS remained unchanged although the PCCL rose to 2. With the addition of R33 retention of urine, the cost weight increased to 4.33, LOS to 14.35 days and PCCL to 3. Thus incontinence alone had no effect, but retention of urine increased resource utilisation.

Because age can affect AR-DRG assignment, the same exercise was run using a 43 year old male, but the results were identical.

Example 4

A 50 year old female with unstable angina (F72bB) had a cost weight of 0.89 and LOS of 3.3 days. With the addition of R32 incontinence, the cost weight increased to 1.31 and the LOS to 5.36 days. If her angina was accompanied by coronary angiography and left ventriculography, in the presence of the incontinence, the cost weight rose to 1.46, but the LOS fell to 4.34 days. If the incontinence was then subtracted, the cost weight remained at 1.46 and the LOS at 4.34 days. Therefore, the incontinence had an effect upon simple angina, but the effect was not seen if she also had complex diagnostic procedures.

Example 5

A 43 year old male who underwent coronary bypass surgery (F06bB) had a cost weight of 4.54 and LOS of 7.43 days. The addition of R32 incontinence did not change the cost or the LOS. Adding another complication, such as deep venous thrombosis (F06aA), increased the cost weight to 6.22 and the LOS to 9.51 days. Subtracting the incontinence from these total events did not reduce either cost or LOS. Thus, in this case, incontinence had no effect upon coding whatsoever.

Example 6

A 50 year male with simple benign prostatic hypertrophy (M61bB) had a cost weight of 0.48 and LOS of 1.87 days. The addition of unspecified incontinence did not change the cost or LOS. Adding transurethral resection of the prostate (M02bB) gave a cost weight of 1.26 and LOS of 3.94 days. Removing the incontinence did not reduce the cost weight or LOS. Thus incontinence had no discernable effect on the DRG assignment in this scenario for prostatic hypertrophy or transurethral resection of the prostate.

Example 7

A 50 year old female who was admitted for an operation for stress incontinence (N06zZ) had a cost weight of 1.29, LOS of 4.39 days and PCCL of zero. Her principal diagnosis was stress incontinence N393. The addition of retention of urine R33 did not change the cost weight or LOS. Adding suprapubic

cystotomy drain did not change cost weight or LOS, but PCCL increased to 3. Hence retention of urine or insertion of a suprapubic catheter did not alter the Cost Weight.

Example 8

A 50 year old female admitted for vaginal hysterectomy (N04zZ) had a cost weight of 1.48, LOS of 4.66 and PCCL of zero. With the addition of R33 retention of urine, cost weight and LOS did not change, but PCCL rose to 3. Adding a suprapubic catheter did not change the cost weight, LOS or PCCL.

Example 9

A 25 year old female hospitalised for spontaneous vaginal delivery of a term infant (O60) had a cost weight of 0.92, LOS of 3.08 days and PCCL of zero. The additional secondary diagnosis of stress incontinence did not change the cost weight or LOS, although the PCCL rose to 1. Adding unspecified incontinence did not change the cost weight or the LOS, but PCCL rose to 2. While the occurrence of incontinence in the postpartum period demands increased nursing care and often increases the period of hospitalisation, this increased resource use does not appear to be reflected in the DRG assignment.

Example 10

A 26 year old female underwent uncomplicated caesarean section delivery (O01dD) with a cost weight of 1.68, LOS of 5.08 days and PCCL of zero. The addition of N393 stress incontinence did not change the cost weight or LOS, although the PCCL rose to 2. Adding R33 urinary retention with suprapubic cystostomy drain did not alter the cost weight or the LOS, while PCCL rises to 2.

11.1.3 Results for Faecal Incontinence

The same hypothetic scenarios were repeated, with the addition of faecal incontinence and in some cases, faecal impaction was added.

Example 1

A 65 year old female with dementia (B63Z) had AR-DRG cost weight of 2.45, LOS 13.95 days, PCCL 0. R15 faecal incontinence was added: the cost weight and the LOS did not change but PCCL became 2.

Example 2

A 50 year old female with uncomplicated stroke (B70C) had a cost weight of 1.48 and LOS of 6.82 days. Faecal incontinence R15 was added: the cost weight, LOS and PCCL remained the same.

Example 3

An 85 year old male with fractured femur after a fall in hospital required general anaesthesia for open reduction and internal fixation and thus was grouped into 108B which has a cost weight of 2.94, LOS of 9.23 days and PCCL of 0. If R15 faecal incontinence was added, the cost weight, LOS and PCCL remained unchanged. With the addition of K564 faecal impaction, the cost weight increased to 4.33, LOS to 14.35 days. Thus faecal incontinence alone had no effect, but faecal impaction increased resource utilisation.

Examples 1 to 3 were repeated with a 64 year old male but the results of the cost weights, LOS and PCCL were the same.

Example 4

A 50 year old female with unstable angina (F72B) had a cost weight of 0.89 and LOS of 3.3 days. With the addition of R15 faecal incontinence, there were no changes to the cost weight or the LOS. If her angina was accompanied by coronary angiography and left ventriculography, in the presence of faecal incontinence, the cost weight rose to 4.54, but the LOS rose to 7.43 days and the PCCL to 2. The addition of K564 faecal impaction resulted in an increase in the cost weight to 6.22, LOS to 9.51 and the PCCL to 3.

Example 5

This scenario (coronary bypass surgery) was not repeated for faecal incontinence, as cardiac surgeons would be unlikely to operate in the presence of faecal incontinence.

Example 6

A 64 year old male with simple benign prostatic hypertrophy (M61B) had a cost weight of 0.48 and LOS of 1.87 days. The addition of R15 faecal incontinence did not change the cost or LOS. Adding K564 faecal impaction gave an increased cost weight of 1.22 and LOS of 5.38 days and PCCL of 3.

Example 7

A 50 year old female who was admitted for an operation for stress incontinence (N06Z) had a cost weight of 1.29, LOS of 4.39 days and PCCL of zero. Her principal diagnosis was stress incontinence N393. The addition of R15 faecal incontinence did not change the cost weight or LOS. Adding faecal impaction K564 did not change cost weight, LOS or PCCL.

Example 8

A 50 year old female admitted for vaginal hysterectomy (N04Z) had a cost weight of 1.48, LOS of 4.66 and PCCL of zero. With the addition of R15 faecal incontinence, the cost weight, LOS and PCCL did not change. Adding K564 faecal impaction did not change the cost weight, LOS or PCCL.

Example 9

A 25 year old female hospitalised for spontaneous vaginal delivery of a term infant (O60) had a cost weight of 0.92, LOS of 3.08 days and PCCL of zero. The additional secondary diagnosis of R14 faecal incontinence did not change the cost weight, LOS or PCCL. Adding K564 faecal impaction did not change the cost weight, LOS or the PCCL.

Example 10

A 26 year old female underwent uncomplicated caesarean section delivery (O01D) with a cost weight of 1.68, LOS of 5.08 days and PCCL of zero. The addition of R15 faecal incontinence did not change the cost weight, LOS or PCCL. Adding R564 faecal impaction did not alter the cost weight, LOS or the PCCL.

11.1.4 Discussion of Results for Part One

The Australian Refined Diagnosis Related Groups is the standard method used by Australian hospitals to cost and reimburse occasions of care in the Acute Setting. As such, it was hoped that patients with neurologic, surgical, medical or obstetric/gynaecological conditions who suffered the co-morbidity of urinary and/or faecal incontinence would be given a higher cost/reimbursement allocation. In the vast majority of cases, this hope was not realised.

In patients with dementia, urinary incontinence did not affect any of the DRG costing, nor did retention of urine and insertion of a suprapubic catheter. This is difficult to understand, since ordinary clinical experience indicates that all of these incontinence sequelae have a major bearing upon the costs of nursing and medical care in such patients.

For patients with stroke, urinary incontinence did affect the Cost Weight, but faecal incontinence did not. In the case of fractured neck of femur, urinary incontinence did not affect the Cost Weight, nor did faecal incontinence. However, urinary retention or faecal impaction did affect the Cost Weight. This indicates that Cost Weight is not very sensitive, as incontinence alone does increase resource utilization.

The situation in unstable angina +/- coronary angiography is probably realistic to some extent, in that the expense of coronary angiography "masks" the effect of incontinence. As regards benign prostatic hypertrophy, it is possible that urinary retention is "part of" the baseline costing for this condition, hence adding it had no effect. Prostatic hypertrophy should NOT be associated with faecal incontinence, but the Cost Weight was unaffected here. It is perplexing that faecal incontinence did affect the Cost Weight for prostatic hypertrophy.

Examples 7, 8 and 10 are common scenarios where the principal diagnosis, prolapse/incontinence surgery or caesarean section, is complicated by urinary retention and management thereof. If untreated, overflow incontinence will result in chronic atonic bladder. Unfortunately, the increased resource utilisation in terms of increased lengths of stay and cost of care associated with these complications which are very apparent in the clinical situation do not appear to change AR-DRG Version 4.1 assignment. It is therefore difficult to see how the present casemix classification system and associated cost weights can appropriately indicate the greater resource requirements of a patient with conditions complicated by incontinence.

11.2 Survey of consecutive series of patients with any incontinence as a secondary diagnosis, discharged over a 30 day period, with cost and LOS data, before and after subtraction of the incontinence

11.2.1 Method

The investigator asked the Clinical Information Department to retrieve a summary of the AR-DRGs and related secondary diagnoses for a consecutive series of "Real" patients who had a secondary diagnosis of incontinence, who were discharged from St. George Hospital between August 1, 2001 and August 31, 2001. This analysis excluded those patients whose principal diagnosis was incontinence. "Incontinence" was defined as any urinary or faecal incontinence.

Using this summary, the clinical coders printed out a complete list of principal diagnoses, Secondary Diagnosis, and cost weights with LOS data for each individual. They then ran the same patient information through the DRG software, but subtracted the code for urinary incontinence. Cost weights and LOS data were compared to see whether the subtraction of the incontinence affected the cost weights or the LOS.

11.2.2 Results

There were 41 patients with a Secondary Diagnosis of any incontinence who were discharged from St. George Hospital over the one month period of August 1 – 31, 2001. Of these, 13 were male, 28 female. Ages ranged from 34 – 93 years.

Five patients who also had a principal diagnosis of urinary incontinence were excluded from the study. Of the remaining 36 cases, subtraction of the diagnosis of incontinence reduced the cost weight and the LOS in only two patients: an 81 year old female with stroke and hemiplegia (similar to example 2 in Part One) and an 86 year old male with pneumonia, left ventricular failure, R32 incontinence, and cerebral infarction. His cost weight decreased from 2.44 to 1.53, and his LOS fell from 10.36 days to 6.76 days, after subtraction of the R32 incontinence diagnosis.

No changes resulted from the subtraction of incontinence from the diagnosis in the remaining 34 cases. In four cases, the patients had the co-morbidity of faecal incontinence. In all of these cases, the patients had multiple secondary diagnoses, generally including dementia or stroke.

11.2.3 Discussion

At a teaching hospital with 545 beds and 3,800 separations per month, there were only 36 patients coded for the co-morbidity of "any incontinence" in one month. This finding casts doubt upon the accuracy of the coding system (which is further substantiated in Part Four of this Pilot Study, 11.4.1). In the 36 cases where incontinence was coded subtraction of the diagnosis affected the Cost Weight in only two cases, which does not reflect the clinical reality.

11.3 Survey of all patients with a primary disease code of urinary or faecal incontinence admitted over 12 months

11.3.1 Methods

The investigator asked the Clinical Information Department to run a printout of all patients admitted to St. George Hospital between Jan. 01, 2001 and Dec. 31, 2001 who had a primary diagnosis of either urinary or faecal incontinence. The total number of admissions to the hospital over that year was 45,975.

11.3.2 Results

Over 12 months there were 47 patients with a principal diagnosis of urinary incontinence. All of these underwent either surgery for incontinence or cystoscopy. There were 10 further patients admitted with the principal diagnosis of faecal incontinence, 2 having graciloplasty, 2 with bowel cancer, 1 having sphincteroplasty, 2 having colonoscopy, 3 having no procedure.

11.3.3 Discussion

It is suspected that the coding of a primary diagnosis of incontinence at this hospital is not accurate. Aside from the Chief Investigation (K.H. Moore) who is a urogynaecologist and performs operations mainly on patients with incontinence, there are 3 other gynaecologists with a special interest in incontinence who also perform such operations. There are also 6 urologists, most of whom undertake continence procedures. Hence the number of 57 patients is likely to be an under-measurement.

Similarly, there are 2 colorectal surgeons with a major interest in faecal incontinence, so that it is unlikely that only 10 operations for this condition were performed in the preceding 12 months.

Therefore, the DRG coding of incontinence diagnoses is not likely to be useful for future economic analyses.

11.4 Retrospective Study of Casemix Coding of Notes for Inpatients Referred to the Nursing Continence Service at St. George Hospital

11.4.1 Introduction

The simulated exercise of DRG coding had shown that patients with incontinence were seldom given a higher cost weight for their episode of care than those without incontinence. Nevertheless, the Nursing Continence Service provides many occasions of service to patients with incontinence of urine or faeces on the wards of St. George Hospital. This service is staffed by three fulltime equivalent Nurse Continence Advisors (NCAs) at the CNS or CNC level of remuneration. Considerable expense for consumables is involved, and a bladder scanner (cost $7,000) is available for dedicated use by ward staff. Furthermore, patients who have sufficient incontinence to require a referral to the Nursing Continence Service presumably also require more care by the ward nurses, as well as extra consumables or linen changes.

Therefore a study was undertaken to test whether those patients who were seen by the Nursing Continence Service for incontinence of urine and/or faeces, were actually coded as having incontinence by the medical coders of the hospital.

On each occasion of service, the NCA applied a "green sticker" to the clinical notes. The type and degree of severity of incontinence was briefly summarised in the notes, with a summary of investigations, treatments, and follow up plan. These clinical notes were the source data for the study.

11.4.2 Methods

The same consecutive series of 80 patients who were elderly, frail elderly, suffering from neurological disorders/dementia, or who were incontinent women of childbearing age, as described in Substudy 2, were studied. The ten women of childbearing age were referred from 15 Feb 2000 to 27 July 2001, because they are less commonly referred to the Nurse Continence Service. The 70 remaining patients were referred from 2 May 2001 to 12 February 2002. This sample was chosen from a consecutive series of referrals in order to study the target groups for this Cost Project (dementia, etc.), but many other patients under age 65 who were not women of childbearing age were also seen by the service during this time, as already discussed.

The source data included the White Index Cards that the NCAs recorded prospectively as part of their own record of the occasions of service. These White Cards provided the consecutive recruitment of the patient series, and provided much information about clinical activities.

Their hospital case notes were extracted and the following data recorded:

1. Demographics: age, sex, incontinence class code (e.g. frail elderly, women of child bearing age).
2. Date of admission and discharge, with duration of stay.
3. The AR-DRG codes on the computerised front sheet were then noted, and the presence of a code for any of the following was ascertained:
   a) any type of urinary or faecal incontinence
   b) urinary retention
   c) urinary tract infection

The latter two items were included because urinary retention may provoke incontinence if untreated and urinary tract infection is known to manifest as incontinence in the elderly female with a somewhat incompetent urethra. Nevertheless, the main outcome measure was a positive recording of any urinary or faecal incontinence on the DRG.

Next, the occurrence in the clinical notes of a comment about the presence of urinary incontinence upon discharge or within the last 7 days of the hospital stay was noted. This was because the AR-DRG coding manual specifies that incontinence should only be coded if it is present upon discharge or within the last 7 days of the stay (Australian Coding Manual 2000).

The data from the hospital notes were checked against the White Cards held by the Nursing Continence Service for each of these patients. The admission dates for the occasion of service by the NCA were checked (as often patients had multiple admissions but the NCA was only called to visit them during one admission). The number of visits by the NCA to the patient was recorded, and the investigations, comments and treatments provided by the NCA were logged onto an Excel data base. Usually the NCA commented upon the duration and/or severity of incontinence, which was relevant to the theoretical likelihood that the incontinence would be coded by the casemix department.

The issue of transient incontinence was also studied, based on the notes made by the NCA on her White Card. If the incontinence was quite intermittent or resolved quite clearly before discharge, this incontinence was coded as "*transient*" on the Excel database.

11.4.3 Results

The mean age of this sample of the clients referred to the nursing continence service was 74.8 years, SD 19, with a median age of 81.5 years, inter-quartile (IQR) range of 70.75- 87, indicating skewed data resulting from the 10 younger women.

The mean number of days in hospital was 24.33 days, SD 20.45, with a median of 18 days, IQR of 11-30, range 3–111 days. The mean number of visits by a Nurse Continence Advisor was 2.48, SD 1.33 visits, with a median of 2, IQR 1-3, range 1-7 visits.

The correlation coefficient between mean number of days stay and mean number of nurse visits was r = 0.374, p = 0.0013, but this is only logical. Interestingly, there was a slightly negative correlation between age and number of nurse visits (r = -0.02, clearly not significant).

Table 20 shows the number of patient notes obtained from clinical information, the others being in use. The number of patients not yet coded at time of analysis was small (n = 2). The number of patients with transient leakage only, that had obviously resolved seven days prior to discharge, is shown. Of the remaining patients with documented incontinence (green NCA sticker with clinical notes about incontinence), the number with a positive coding for any incontinence are shown.

Table 20 Urinary incontinence codes for inpatients referred to the Nursing Continence Service*

	Notes available	Not Coded	Available	Transient Leakage	Remainder	No. Coded		Incomplete coding
Childbearing N = 10	N = 10	0	10	2	8	0		8/10 (80%)
Dementia N = 11	N = 8	0	8	0	8	5	Retention = 3 Incontinence = 1 UTI = 1	3/8 (37%)
Elderly N = 20	N = 17	0	17	2	15	4	Retention = 1 Incontinence = 1 UTI = 2	11/15 (73%)
Frail Elderly N = 19	N =18	2	16	4	12	8	Retention = 1 Incontinence = 4 UTI = 2 Catheter infection = 1*	4/12 (33%)

Neurological N = 21	N = 21	0	21	6	15	7	Urinary Incontinence = 2 UTI = 4 Urinary + Faecal Incontinence = 1	8/15 (53%)
Total = 81	74	2	72	14	58	23		**34/60 (56.6%)**

*Note that the percentage figures for childbearing etc are ROW percentages, whereas the percentage figure for the total is a COLUMN percentage. Also note that we allowed the coders to mistake transient incontinence as a legitimate mistake.

On the face of it, the figure of 56.6 per cent incomplete coding for the presence of incontinence in this small sample might seem very large. However, scanning of the often poorly legible discharge summaries in the clinical notes (not the "front sheet" summaries completed by medical staff well after the discharge) indicate that incontinence was mentioned by medical or nursing staff in only 22 cases of the 74 notes reviewed (30 per cent), so that the discharge summaries were incomplete in 70 per cent of cases. Thus the coding staff had succeeded in identifying the problem 14 per cent more often than had the clinicians involved in the care of the patients. The scrutiny of these discharge summaries was not exhaustive however, as the main outcome of interest was the clinical casemix coding of incontinence.

An even more difficult area was that of faecal incontinence. The notes of the ward clinicians and of the NCAs were often not very descriptive of the problem of faecal incontinence, so that it was difficult to record this outcome in the present analysis.

11.4.4 Conclusions

The first issue that has a great impact upon the planning of Project 3 – Field Studies, is that of the AR-DRG coding stipulation regarding transient incontinence. On the one hand, if a patient has an isolated episode of incontinence associated with being acutely unwell, it is logical that it should not be coded, as little work will be done to care for this patient's problem. If, on the other hand, the patient is in hospital for a long stay (note maximum stay of 111 days in this sample) but is not incontinent for the last seven days of the stay, then the AR-DRG manual indicates that the problem should not be coded, which is not logical.

In substudy 2, it has been shown that the care of incontinent patients costs between $39 and $59 in NCA time alone, not to mention all the time spent by the ward staff in caring for the problem or the linen/consumables involved. This care is especially important if it results in the resolution of the incontinence problem. At present, the cost of such curative care is seldom reflected in cost weights because transient incontinence is not coded. In Parts 1 and 2 of this sub study (the simulated study of casemix coding), we have shown that even a correct coding of incontinence seldom results in any increase in the cost weight for the patient. Thus it would seem that current coding methodology will not be useful in measuring the costs of incontinence in Australian acute care hospitals.

Secondly, the rather variable casemix coding for urinary infection was an unexpected finding. On several occasions, patients with incontinence were found to have a urinary tract infection (UTI) associated with their incontinence, although this was not a target for study in the present sample. In most of these cases, UTI was not coded either. This problem has not been systematically recorded because scrutiny of the microbiology reports would have been necessary, and was not possible within the time frame. We have included UTI as a significant coding event, because it indicates that the coders were detecting the problem on some occasions. We have not ascertained the denominator for this problem, i.e. the number of proven UTIs in the sample was not measured.

Finally, as previously mentioned, an entire group of incontinent patients were not included in the present study because they were not included in the Tender Specifications for Project 2. These are the patients who are not elderly (age < 65), not demented, not neurologically impaired and not women of childbearing age. Many patients who are aged 40 – 65 years do suffer from incontinence, but they have not been captured by any part of this project except the in Substudy 3 regarding patients attending the Pelvic Floor Unit as outpatients for one week. Certainly the median age of women with urge incontinence is 55 years, as previously published by our group, and the median age of patients seeking treatment for stress incontinence is generally reported to be about 50 years.

Section 12. Substudy 6: Analysis of An-Snap Study Database

12.1 Background

In 1996, the Centre for Health Service Development, University of Wollongong, was commissioned jointly by the Commonwealth and New South Wales Department of Health to undertake a study to develop a national casemix classification for sub-acute and non-acute care. This study involved 104 sites across Australia (99) and New Zealand (5), including public and private hospitals and community services. These sites collected detailed clinical and costing data for sub-acute and non-acute episodes of care over the three-month duration of the study. Data were collected for a total of 30,604 episodes of care and this information was used to develop the Australian National Sub-acute and Non-Acute Patient Classification (AN-SNAP) (Eagar et al. 1997).

AN-SNAP consists of five sub and non-acute **Case Types** [Palliative Care, Rehabilitation, Psycho geriatric, Geriatric Evaluation and Management (GEM) and Maintenance], encompassing four treatment settings: Overnight inpatients (where the patient is admitted to hospital for one or more nights); Same Day Admitted (where the patient is admitted and discharged on the same day); Outpatient; and Community (Eagar et al. 1997). These four treatment settings are referred to as **Episode Types**.

12.1.1 Current Analysis

Because the AN-SNAP database includes categorisation for patients with bowel and bladder dysfunction or incontinence, it seemed appropriate to undertake a retrospective analysis of this dataset. Thus Substudy 6 consists of a retrospective analysis of the original 1996 AN-SNAP database (hereafter SNAP Study database), undertaken by Irenie Smoker, who was formerly a SNAP Coordinator with the NEW Department of Health, and Janette Green Senior Research Fellow in Applied Statistics, Centre for Health Service Development, University of Wollongong, who was involved in analysis of the original data, and the subsequent establishment of the AN-SNAP casemix classification. Input was also provided by Dr. T Ho and A/Prof. K Moore. The aims of this analysis were to:

- Establish whether daily costs of treating patients with incontinence conditions were higher than those of treating patients who are continent,
- Identify variables that contributed to the daily cost of treatment, and
- Investigate the increase to the cost that can be attributed to incontinence, if possible.

12.1.1.1 Continence Status

As part of the clinical data collection in the AN-SNAP study, the UDS Functional Independence Measure (FIM™) (Centre for Functional Assessment Research, Uniform Data System for Medical Rehabilitation 1993) was collected for two of the five Case Types (Rehabilitation and GEM). The FIM is a measure of independence comprising eighteen items, including motor and cognitive items. These items are scored using an integer between 1 and 7, with a 1 indicating total contact assistance (or complete dependence) and a 7 complete independence. Two of the motor items categorize incontinence (bladder management and bowel management). Thus continence status was available for Rehabilitation and GEM patients, and the case types of Palliative Care, Psycho geriatric Care and Maintenance Care are not considered further in this analysis.

12.1.1.2 Costing components

In the AN-SNAP study, costs were collected and assigned to one of 12 different cost "buckets", which were divided into two main groups. Firstly, "core costs" comprised nursing, allied health (physiotherapists, occupational therapists, speech therapists, social worker, psychologists, dieticians, podiatrists) goods and services and medical and surgical supplies (equipment, prostheses, patient transport). Secondly, "other non core costs" comprised medical costs, imaging, pathology, and pharmacy, capital and volunteer time. For ambulatory patients (same day, outpatient and community) medical costs were also included in the core cost. Medical costs were not included in the main "core costs" for inpatients because they could not be costed accurately. This occurred because doctors were paid in a variety of ways, across the public and private settings within the data collection sites. Also, medical costs were inconsistently reported in general, so the data was very inaccurate.

In the AN-SNAP study, only the core costs were used to develop the classification. The cost per day was defined as the core cost divided by the number of days on which data were collected. For inpatient

episodes, data were collected daily. For same day, outpatient and community episodes, data were collected each day that care was provided. Details of the AN-SNAP costing method is provided in Eagar et al. 1999 (pages 46-47).

These "non-core costs" could not be collected consistently across both the public and private sectors, so they were excluded from analysis. Nursing and allied health staff costs were derived from log sheets of staff time and represented almost 60 per cent of total core costs. As previous authors have shown that pathology and pharmacy costs are greater for incontinent patients, this study focuses on the "core staff costs", about which little is known in the field of incontinence. Our analysis therefore only included nursing and allied healthcare costs. All costs are in 1996 Australian dollars.

Definitions

The **quantum of care** was an episode, defined as a period of contact between a patient and a provider occurring in one setting and in which there is no major change in the goal of intervention.

The **length of stay** (LOS) was defined as the number of days on which care was provided, and was calculated as the end date minus the admission date plus one.

The **cost per day** was calculated by dividing the core costs (nursing and allied health staff costs) by the number of days on which care was provided.

12.1.1.3 Trimming of the data

There were a total of 15,681 Rehab and GEM episodes of care in the SNAP Study database. However, FIM scores were not available for all patients within these two Case Types. Some sites had used the Barthel Index rather than the FIM to measure functional independence. The FIM score was not collected for patients presenting for assessment only. Thus there were 9,554 episodes of care within the SNAP Study database that were considered to be potentially suitable for inclusion in the current analysis.

Prior to analysis, outliers were removed as follows. Each Case Type/Episode Type subgroup was examined separately. A conservative trimming method was adopted (the standard inter-quartile range trim applied to the natural logarithm of the per diem costs) to avoid the possibility of trimming out a whole subgroup in the data set. For example, severely impaired brain injury patients may all have very high daily costs, but it was inappropriate to trim out all of one type of episode such as this. The resulting data set for this analysis comprised 9,418 episodes of care.

12.1.1.4 Descriptive Analysis of the Data Set

From the large number of variables available for each episode of care, the variables known to be relevant to incontinence were considered i.e. age, functional impairment group (as defined by the UDS_{MR} Functional Impairment Codes Version 4), Case Type and Episode Type. An overview of these data is presented in the following.

Table 21 Number of Episodes in each AN-SNAP Case Type by treatment setting (Episode Type)

Case Type	Episode Type Inpatients	Same Day Admitted	Outpatients	Community	Total
Rehab	5660	315	985	330	7290
GEM	1113	128	29	858	2128
Total	6773	443	1014	1188	9418

Of the 9,418 episodes outlined in Table 21, 77 per cent were rehabilitation episodes and they were predominantly inpatients (72 per cent). All Rehabilitation and GEM episodes were allocated to one of 16 UDS Impairment Categories, as shown in Table 22. The most common impairment categories were Orthopaedic Conditions and Stroke.

Table 22 Number of Episodes in each Impairment Category

Impairment Category	Number of Episodes	Percentage in Each Group
Orthopaedic Conditions	2561	27.19
Stroke	1772	18.82

Brain Dysfunction	775	8.23
Pain	761	8.08
Neurological Conditions	585	6.21
Debility	515	5.47
Other Disabling Impairments	503	5.34
Cardiac	420	4.46
Amputation Of Limb	394	4.18
Spinal Cord Dysfunction	364	3.86
Pulmonary	357	3.79
Arthritis	286	3.04
Major Multiple Trauma	86	0.91
Burns	15	0.16
Developmental Disabilities	13	0.14
Congenital Deformities	11	0.12
Total	9418	100.00

The bladder management item in the FIM instrument (scored between 1 and 7) was used to define bladder incontinence. Score 1 was given to patients who were totally dependant for help with managing their bladder. Score 7 was given to those who were completely self-caring of bladder management.

The numbers of episodes of care in each possible score for bladder management upon admission is shown in Figure 4. The majority of episodes were scored a 7 (completely self-caring). Table 23 shows bladder management scores in relation to case type (Rehabilitation/Geriatric Management).

Figure 4 FIM bladder management admission score by number of episodes

Table 23 Bladder Management Score on Admission by Case Type

Bladder management Score	**Rehab**		**GEM**		**All**	
	Number	Percentage	Number	Percentage	Number	Percentage
1 (complete dependence)	818	11.2%	261	12.3%	1079	11.5%
2	288	4.0%	153	7.2%	441	4.7%
3	254	3.5%	115	5.4%	369	3.9%
4	283	3.9%	107	5.0%	390	4.1%
5	613	8.4%	167	7.8%	780	8.3%
6	1020	14.0%	313	14.7%	1333	14.2%
7 (complete independence)	4014	55.1%	1012	47.6%	5026	53.4%
Total	7290		2128		9418	

In Table 23, the majority of episodes (53.4 per cent) were scored 7 for bladder management (fully independent). More Rehabilitation episodes scored completely independent than GEM episodes (55.1 per cent versus 47.6 per cent), as was expected.

Table 24 presents the bladder management score by EpisodeType. It was more common for ambulatory episodes (same day admitted 75.4 per cent, outpatient 83.3 per cent, and community 60 per cent) to be scored as completely independent compared to inpatient episodes (46.3 per cent).

Table 24 Bladder Management Score on Admission by Episode Type

Bladder management Score	Inpatient		Same Day Admitted		Outpatient		Community	
	Number	Per cent	Number	Per cent	Number	Per cent	Number	Per cent
1 (complete dependence)	933	13.8%	19	4.3%	38	3.7%	89	7.5%
2	356	5.3%	11	2.5%	10	1.0%	64	5.4%
3	310	4.6%	6	1.4%	12	1.2%	41	3.5%
4	327	4.8%	6	1.4%	11	1.1%	46	3.9%
5	658	9.7%	25	5.6%	26	2.6%	71	6.0%
6	1055	15.6%	42	9.5%	72	7.1%	164	13.8%
7 (complete independence)	3134	46.3%	334	75.4%	845	83.3%	713	60.0%
Total	6773		443		1014		1188	

The two largest impairment groups of rehabilitation patients – orthopaedic and stroke patients – were selected for a more detailed analysis. For each of these impairment groups, we selected only those patients whose continence status remained unaltered throughout their episode of care, so as to facilitate the statistical analysis. The orthopaedic dataset comprised 1599 episodes from 39 facilities, while the stroke dataset consisted of 887 episodes from 40 facilities.

Figure 5 and Figure 6 present the numbers of episodes of care in each possible score for bladder management for stroke and orthopaedic cases. The different scales on the vertical axes should be noted when comparing the bar charts. Although most patients were scored as completely independent re bladder care, stroke patients more commonly needed help.

Figure 5 FIM bladder management admission score by number of episodes – stroke

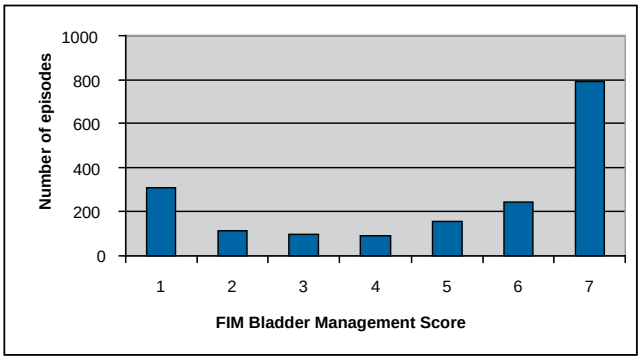
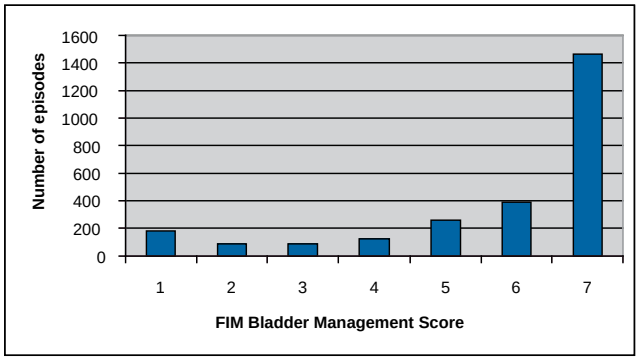
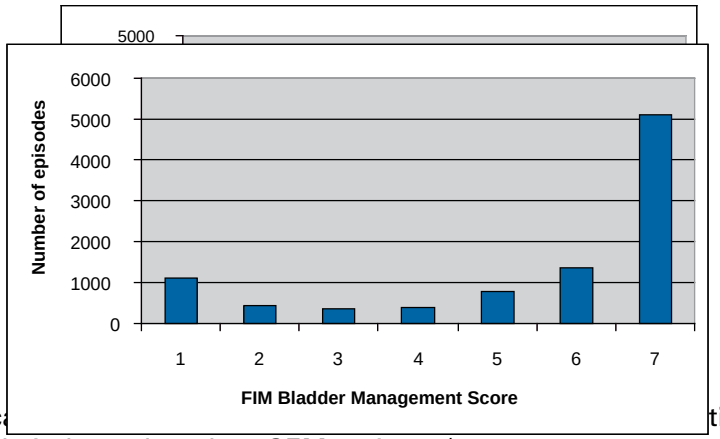


Figure 6 FIM bladder management admission score by number of episodes – orthopaedic



The bowel management item in the FIM instrument was similarly used to define bowel incontinence. Figure 7 presents the number of episodes in each possible score for bowel management on admission. Again, the majority of episodes (49.4 per cent) were scored a 7 for bowel management, but there were a number of episodes scoring a 6.

Figure 7 FIM bowel management admission score by number of episodes – complete data set



With regard to the c tion patients were more likely to be completely independent than GEM patients (50.8 per cent versus 44.5 per cent refer Table 47, Appendix H).

As regards episode type, the proportion of inpatient episodes scored as completely independent for bowel management (40.5 per cent), was lower than for ambulatory episodes (same day admitted (71.3 per cent), outpatient [80.9 per cent] and community [65.1 per cent]), as expected (refer Table 48, Appendix H).

As regards the breakdown for stroke and orthopaedic patients, the histogram describing relative numbers of cases who were complete independent (score 7) shows the same trend as for all the impairment categories depicted in Figure 5 and Figure 6 (Figure 12 FIM bowel score for stroke patients, Figure 13 FIM bowel score for orthopaedic patients are shown in Appendix H).

12.1.1.5 Definition of Incontinence

As discussed above, the FIM items can be scored using an integer between 1 and 7, with a 1 indicating complete dependence and a 7 complete independence. Based on the definitions in the FIM manual for scoring items, it was decided that a patient would be classified as incontinent if their score on the FIM bladder management item on admission was not 7 i.e. was 1-6. Since both bladder and bowel incontinence was of interest, the FIM bowel management item was used in the same way.

Unfortunately, the distinction between continence and incontinence using these FIM items is not as clear-cut as would be hoped. Difficulties were encountered:

- Patients who need to use a bedpan because of mobility problems are often scored 5 on the bladder management item even though they may not be at all incontinent.
- Patients with constipation may be scored less than 7 on the bowel management item if they required assistance with their bowel care, for example faecal disimpaction, even though they are not incontinent.

Although these patients are not considered to be incontinent, it was determined that all patients scoring less than a 7 would be included in our definition of incontinent as they are likely to require more resources for bladder or bowel management than a patient who is given a score of 7. The authors acknowledge that this is one of the problems with a retrospective analysis of a dataset. Such definitions are likely to inflate the incidence rates of incontinence. It is therefore recommended that any future data collection being designed to measure the cost of incontinence would need to clearly identify those patients who are incontinent, rather than rely upon the scores in the relevant FIM items.

Using the definition based on the FIM score, percentages of patients found to be bladder incontinent, bowel incontinent or both have been calculated (refer Table 25 below).

Table 25 Percentage of patients in the dataset in each continence group

Case Type	Episode Type	Number of Episodes	% Continent	% Bowel Incontinent Only	% Bladder Incontinent Only	% Bowel and Bladder Incontinent
Rehabilitation	Inpatient	5660	36	12	7	45
	Same Day	315	63	10	7	20
	Outpatients	985	79	5	3	13
	Community	330	66	5	8	20
GEM	Inpatient	1113	22	15	5	58
	Same Day	128	68	13	6	13
	Outpatients	29	59	7	7	27
	Community	858	50	6	11	33
Overall		**9418**	**43**	**10**	**7**	**40**

Overall, 43 per cent were completely continent, while 40 per cent were both bladder and bowel incontinent. When these figures are broken down by treatment setting and Case Type it was found that GEM patients were generally more likely to be incontinent than Rehabilitation patients. Inpatients were more likely to have continence problems than any of the ambulatory patients (same day, outpatient and community). This is not a surprising result, as a continence problem may well influence the choice of treatment setting.

Within most groups, a problem with bowel continence seems to be more prevalent than a problem with bladder continence. This may be due to the issue outlined above where the definition means that patients with bowel impaction are included in the incontinent group (i.e. score less than 7). The exception to this pattern is found in Community patients where bladder continence problems are more prevalent.

In 12.2, issues relating to costs of bladder incontinence are investigated. In 12.3, the same investigation into bowel incontinence will be reported.

12.2 Results of analysis of patients with Bladder incontinence in SNAP database

12.2.1 Descriptive Analysis of Bladder incontinence by Case Type, Episode Type and Age

For the total data set, roughly 45 per cent of Rehabilitation patients and 52 per cent of GEM episodes were classed as being bladder incontinent. Proportionally more patients treated in as inpatients were incontinent (54 per cent) than those treated in ambulatory settings (25 per cent of day only admissions, 17 per cent of outpatients and 40 per cent of community patients).

Table 26 shows the impairment groups taken from Table 22, with the percentage of each of these groups who were incontinent.

Table 26 Percentage Bladder Incontinent by Impairment Group

Impairment Group	Percent Incontinent	No. in Impairment Group
Spinal Cord Dysfunction	**76.9%**	**364**
Congenital Deformities	**63.6%**	**11**
Debility	**60.4%**	**515**
Burns	**60.0%**	**15**
Stroke	**55.7%**	**1772**
Neurological Conditions	**52.1%**	**585**
Major Multiple Trauma	50.0%	86
Other Disabling Impairments	48.3%	503
Pulmonary	48.2%	357
Brain Dysfunction	47.9%	775
Developmental Disabilities	46.2%	13
Amputation Of Limb	45.7%	394
Orthopaedic Conditions	43.4%	2561
Cardiac	34.8%	420
Arthritis	31.8%	286
Pain	17.1%	761

In six of the sixteen impairment groups, more than 50 per cent of patients were classified as incontinent (shown in bold). Of the two largest impairment groups, only 43 per cent of patients with Orthopaedic Conditions had incontinence, while Stroke patients were incontinent in 56 per cent.

Figure 8 shows the relationship between age and bladder incontinence.

Not surprisingly, the older age groups had the highest proportion of incontinent patients, with the exception being the 0-9 age group.

Figure 8 Bladder continence/incontinence by age group – all patients

The data shown in Figure 8 is further broken down into Rehab/GEM patients and into the 4 episode types in (Figure 14, Figure 15, Figure 16, Figure 17, Figure 18 and Figure 19 of Appendix H).

As would be expected, proportionally more of the older patients were classified incontinent.

12.2.2 Relationship of continence to discharge destination

The reason for the completion of the care episode was collected as a data item in the SNAP Study. Possible categories for discharge are listed below in Table 27.

Table 27 Reason for Episode End for Inpatient Episodes

End Reason	Percent of Continent Group	Percent of Incontinent Group
Discharged to nursing home	4.6%	13.0%
Discharged home	82.1%	57.3%
Died	0.7%	2.9%
Continued in care after episode end	7.8%	16.0%
Discharged at own risk	0.5%	1.0%
Statistical discharge from leave	0.2%	0.2%
Episode incomplete at end of data collection	4.1%	9.6%

From Table 27, more than 82 per cent of patients with no continence problem were discharged home at the end of their episode, but this was true for fewer than 60 per cent of the incontinent group. Instead, those with an incontinence condition were more likely to go to a nursing home or to move on to further care. Their episodes were also more likely to still be in progress when the data collection ceased, reflecting a longer average length of stay for these patients. Of course, other differences between the two groups such as average age and other FIM scores would contribute to this finding. There is no statistical evidence that incontinence alone would result in these differences.

12.2.3 Results for Bladder Incontinence Analysis:

Average Length of Stay (LOS) and Average Daily Costs

One of the aims of this study was to determine whether continent and incontinent patients differed in length of stay (LOS) and average daily cost. However, the calculation of the average LOS was not a straightforward task. Complete LOS was only available for some episodes because the data collection period only lasted 3 months. Some patients were already in care at the time of starting data collection and some patients remained in care at the end of the data collection period. For many of those who were still in care at the end of data collection, the date on which their episode of care ended was not known: these patients were excluded for calculation of the average LOS. In the current analysis, LOS for each episode was calculated as the number of days on which care was provided between the days

that the FIM assessment was made (generally at the beginning of an episode) and the last day of the episode (when known). The total number of patients could still be used to analyse average daily costs.

Table 28 Average Daily Cost and Length of Stay for Subgroups

(N values = numbers with reliable LOS data)

Case Type	Episode Type	Continence Status	Number of Episodes	Average LOS	Average Cost Per Day	p-value for diff in cost
Rehabilitation	Inpatient (n = 5255)	Continent Incontinent	2722 2938	20.6 28.5	$236 $275	<0.001*
	Same Day (n = 247)	Continent Incontinent	230 85	40.0 34.5	$121 $164	<0.001*
	Outpatients (n = 683)	Continent Incontinent	826 159	51.0 44.4	$71 $77	0.121
	Community (n = 280)	Continent Incontinent	236 94	62.7 65.8	$76 $80	0.452
GEM	Inpatient (n = 1080)	Continent Incontinent	412 701	17.5 19.3	$159 $206	<0.001*
	Same Day (n = 121)	Continent Incontinent	104 24	54.5 58.7	$93 $96	0.707
	Outpatients (n = 27)	Continent Incontinent	19 10	78.5 53.6	$64 $85	0.104
	Community (n = 697)	Continent Incontinent	477 381	59.3 65.2	$72 $71	0.884
Overall			9418	$199	31.3	

* Difference is statistically significant at 5 per cent level

It can be seen that there were consistently higher costs for the incontinent group. The difference was found to be statistically significant **in three groups** (see values with an asterisk). The higher costs may not have been caused by the incontinence. Many other factors differ between the two groups as well. For example, the incontinent patients tended to be older, and to have lower scores on other FIM items. This question is investigated further, for specific impairment groups.

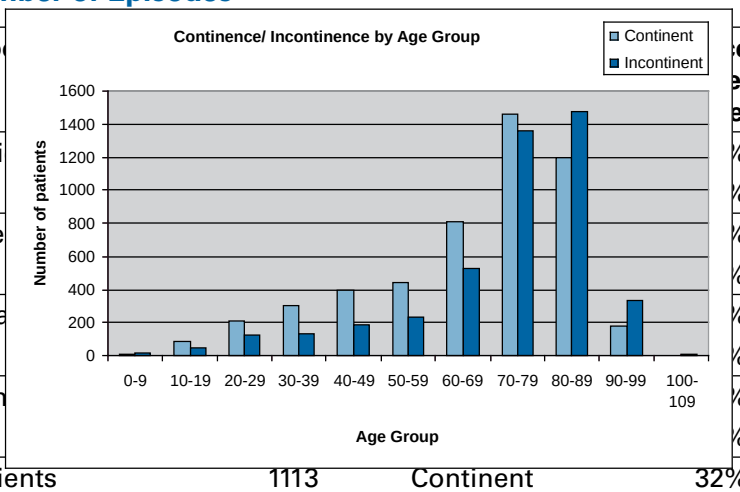
12.2.4 Maintaining Continence Status over duration of Episode: Cost Comparisons

Continence status was assessed at admission, but what if a patient had become incontinent during the episode? FIM scores at episode end were used to assess change in continence status across the episode. The percentage of each group that maintained their continence status was calculated and used to compare the daily cost of those who remained incontinent (or continent) and those who changed.

There are four possibilities for continence status. Patients may have been continent at the beginning of the episode and either remain continent, or become incontinent by the end of care. On the other hand they may have begun their episode of care incontinent and either remained incontinent or become continent by the end of their episode.

The number of care episodes displaying each of these four continence patterns within each of the Case Type/Episode Type subgroups was calculated, and then converted to percentages. Table 29 presents the number of episodes of care in each Case Type/Episode Type subgroup, together with the percentage displaying each of the four patterns of continence.

Table 29 Bladder continence status at beginning and end of the episode – Number of Episodes



Case Type	Episo			ent nt at e End	per cent Incontinent at Episode End
Rehab	Inpati			%	3%
				%	36%
	Same			%	<0.5%
				%	22%
	Outpa			%	<0.5%
				%	15%
	Comn			%	<0.5%
				%	26%
GEM	Inpatients	1113	Continent	32%	4%
			Incontinent	12%	52%
	Same Day	128	Continent	77%	4%
			Incontinent	3%	16%
	Outpatients	29	Continent	62%	3%
			Incontinent	0%	35%
	Community	858	Continent	52%	3%
			Incontinent	2%	43%
Overall		9418			

NOTE: Percentages have been rounded to whole numbers. Where the percentage is very small, but not zero, "<0.5" has been recorded.

In Table 29, the percentages for each Case Type/Episode Type subgroup sum to 100. Thus, of the inpatient Rehabilitation episodes of care, for example, 45 per cent began and remained continent, 36 per cent began and remained incontinent, 3 per cent began continent but became incontinent during the episode and 16 per cent began incontinent but were continent by the end of the episode.

It is noted from the above table that when patients began the care episode continent, the majority remained continent. Further, many patients who were incontinent at the beginning remained incontinent throughout the care episode.

However, it is encouraging to see the improvement from incontinent to continent in many patients. This is particularly evident in the overnight admitted Rehabilitation group, where 16 per cent began their episode incontinent, but finished continent. In each treatment setting, proportionally more Rehabilitation patients improved from incontinent to continent than did GEM patients. This is not surprising as the primary treatment goal for Rehabilitation patients was to improve functional status, whereas GEM patients had complex, multi-dimensional medical problems and the primary goal of their treatment was to optimise health status and/or optimise living arrangements.

In the following table, Table 30, episodes of care are grouped in the same way as for the previous table, but the average daily cost in each of these groups is recorded. Within each Case Type/Episode Type sub-group, two-sample T-tests were performed separately on the continent and incontinent (on admission) groups, to see whether average daily costs differed depending on continence status at the end of the episode. (See far right column, p value).

Table 30 Bladder continence status at beginning and end of the episode – Daily Costs

Case Type	Episode Type	Continence Status on Admission	Continent at End – Daily Cost	Incontinent at End – Daily Cost	p-value
Rehabilitation	Inpatients	Continent	$235.03	$258.35	.014*
		Incontinent	$253.32	$285.03	.000*
	Same Day	Continent	$120.47	$134.92	.729

		Incontinent	$192.72	$157.40	.192
	Outpatients	Continent	$70.98	$81.75	.574
		Incontinent	$105.38	$74.93	.129
	Community	Continent	$75.42	$93.45	.491
		Incontinent	$57.11	$82.49	.007*
GEM	Inpatients	Continent	$155.28	$184.02	.013*
		Incontinent	$163.86	$215.49	.000*
	Same Day	Continent	$93.42	$77.95	.298
		Incontinent	$106.05	$94.14	.614
	Outpatients	Continent	$64.26	$54.00	-
		Incontinent		$84.96	-
	Community	Continent	$71.45	$74.15	.730
		Incontinent	$67.69	$71.35	.723
Overall		$180.77	$229.33		

Difference is statistically significant at 5 per cent level

For inpatients, there is a significantly higher cost for those who end their episode incontinent than for those who don't (whether or not they had this problem at the beginning of their care episode). For example, in the first row, patients who began continent and remained continent were the cheapest to care for ($235 per day). Those who began continent but became incontinent were more expensive ($258). Those who began incontinent but became dry were much cheaper to care for ($253) than those who started out incontinent and remained wet ($285). Of course we have no data to explain whether these figures represented "cause or effect". Certainly patients who are continent throughout care should be the cheapest to manage. However, perhaps those who began continent but became incontinent were just very ill or demented? Similarly, those who were incontinent throughout care could have been the frailest patients with the most co-morbidity, thus more expensive because of their other illnesses, not because they needed help with bladder care. In many of the ambulatory groups (same day admitted, outpatients and community) similar trends were observed. However most were not statistically significant because of the small number of episodes in the groups.

12.2.5 Cost of Incontinence in specific impairment groups

As stated above, the aim of this part of the analysis was to:

1. Establish whether daily costs of treating patients with incontinence conditions are higher than those of treating patients who are continent,
2. Identify variables that contribute to the daily cost of treatment, and
3. Investigate the increase to the cost that can be attributed to incontinence, if possible.

There were many variables in the data set that could be contributing to the cost. These included age, FIM motor scores (a subscale of the FIM instrument measuring motor functional ability) at episode beginning and end, FIM cognition score (a subscale of the FIM instrument measuring cognitive functional ability) at episode beginning and end and an RCI behaviour score. It would be expected that a different set of variables would be found for inpatients than those that were relevant for ambulatory episodes. Similarly, cost drivers may differ between patients in the various impairment groups (stroke, orthopaedic, cardiac, etc.). Of course, since this is a retrospective analysis, there is also the possibility that some cost drivers for continence conditions had not been captured in the AN-SNAP study.

To simplify the analysis and to assist with the interpretation of the results, it was decided to isolate two impairment groups and to investigate costs within each of these groups. The groups with the largest number of episodes were chosen – stroke and orthopaedic. Of these, stroke had the higher proportion of incontinent patients.

12.2.5.1 Impairment Group – Stroke

Were the average daily costs of incontinent patients significantly different from the cost of those with no incontinence problem? Independent samples t-tests were conducted within each Case Type/ Episode Type group to test for differences in average daily costs between incontinent and continent stroke patients.

In the subgroup of Rehabilitation inpatients with stroke, the average per diem costs of continent patients ($256, n = 437) was significantly lower than that for incontinent patients ($291 per day, n = 760), ($p< 0.001$) but there was no significant cost difference for the other stroke episode types. Although a similar trend was observed (incontinent patients were more costly), smaller numbers made significance less likely to emerge (Table 50, Appendix H).

Which variables contribute to the overall cost of treatment? Correlations amongst the variables thought to be relevant to the cost of treatment were calculated. These variables included age, FIM cognitive score on admission (total of FIM items 14 – 18), FIM motor score on admission (total of items 1 – 13), change in FIM cognition score from beginning to end of the episode of care, change in FIM motor score from beginning to end of the episode of care, and RCI behaviour total as well as continence status. Correlations between these variables and average cost per day were also calculated, shown in Table 50, Appendix H. Spearman correlations were calculated between the continence status and all other variables. Pearson Correlations were calculated between all other pairs of variables.

All cost correlations coefficients are quite low. The correlation with the FIM motor score on admission is the largest (in absolute value), with a value of –0.25. The negative value means that as the functional motor score increases, the cost decreases. In other words, treating patients who are more severely functionally impaired is more expensive. Correlations between the FIM cognition score and the change in cognition and between the FIM motor score and change in motor score are both negative. This is to be expected as people with higher functional scores are less impaired and have less room for improvement. There is a moderately high correlation between FIM motor and FIM cognition score (0.486, Table 50, Appendix H).

The highest correlation in the table (in absolute value) is that between bladder continence status and FIM motor score on admission. Continence status has been defined using one of the FIM motor items (bladder management) – those defined as incontinent scored less than 7 on the bladder management item, while those scoring 7 were classed as continent. The score on this one item would therefore be lower for incontinent patients. This would have an effect on the total FIM motor score, in that the maximum score they could attain would be 90 rather than 91 (as it is calculated as the sum of 13 items, each scored between 1 and 7). This effect should be minimal and would not be the sole reason for this correlation being so high. It is more likely that the size of the correlation reflects the fact that stroke patients who are incontinent often have other functional impairments.

The next step in the analysis was to model the cost per day using a combination of the other variables. The aim of this modelling was to "explain" the variability amongst costs in terms of other information, such as clinical or demographic data about the patients. Variability amongst per diem costs could be affected by a number of factors. For example, age, mobility, cognitive function and other patient characteristics could all affect the cost of care. As well as these, differences between different medical facilities could also result in different costs. Data had been collected from a number of different facilities and differences between their cost structures would also affect the cost of patient care. Thus the data had a multilevel structure – patients (at the first level) within hospitals (at the second level).

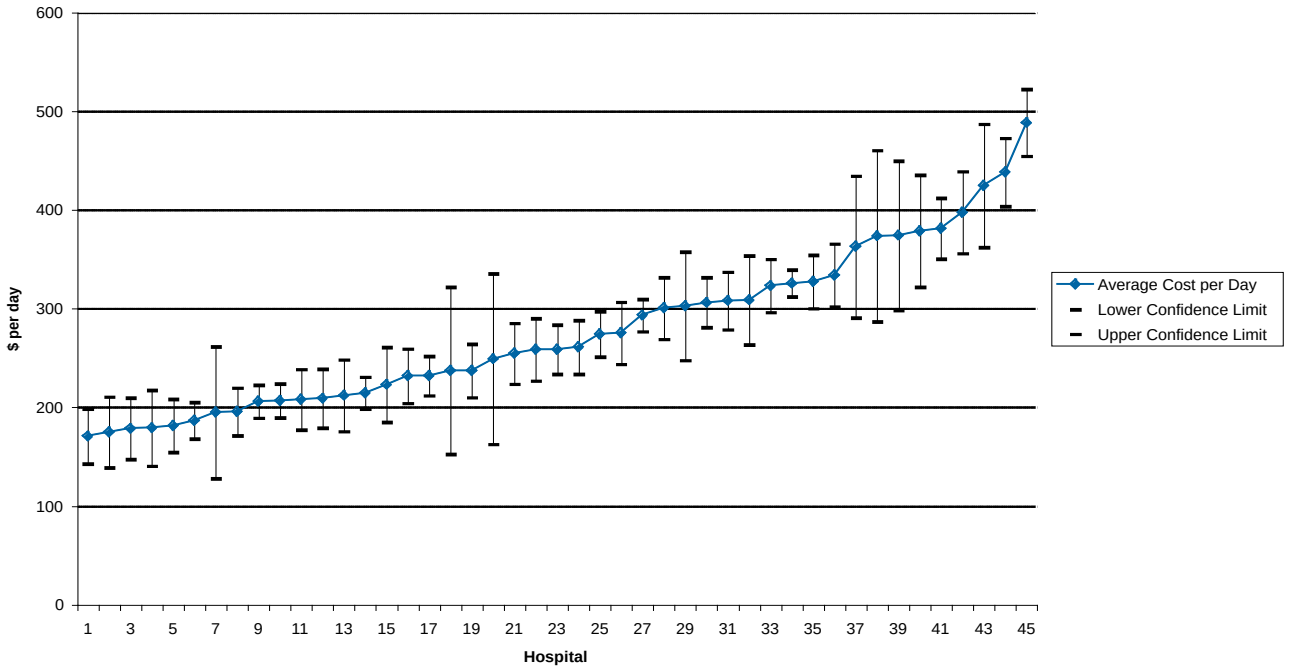
A regression analysis could have been used to model the costs if the aim was not to test the variables for significance. However testing of variables for significance was an aim of the study. The multilevel structure of the data suggested that a multilevel model would be more appropriate. Added to this, 45 per cent of the variability in cost per day was found to be between facilities rather than within facilities. Had a regression analysis been used, the associated significance tests would have been invalid as the standard errors would have been underestimated. Thus it would appear that variables were significant when in fact they were not. This happens because the proportion of variability in costs that was between (rather than within) facilities were so high (45 per cent). This high value results in quite a high correlation between patients within the same hospital. This correlation invalidates the inferences regarding the parameter estimates that are made in a standard regression analysis.

The aim of the multilevel analysis was to separate the variability that could be attributed to patient characteristics from that resulting from differences between facilities. For the current problem, differences between the facilities were of less interest than differences between patients within a facility.

The following graph, Figure 9, shows the average cost per day (with 95 per cent confidence intervals) at each facility, arranged in ascending order.

Figure 9 Rehabilitation Overnight Stroke – Average Cost $ per Day at

Different Hospitals



It can be seen that the average cost per day ranges from less than $200 to almost $500. For the multilevel analysis, rehabilitation stroke inpatients only were included. The response variable was average cost per day. All explanatory variables were fitted – age, FIM cognitive score on admission (total of FIM items 14 – 18), FIM motor score on admission (total of items 1 – 13), change in FIM cognition score from beginning to end of the episode of care, change in FIM motor score from beginning to end of the episode of care, and RCI behaviour total as well as continence status. The resulting coefficients and their p-values are presented in Table 31.

Table 31 Estimated coefficients from multilevel analysis

Variable	Estimated coefficient	p-value
Intercept	280.24	<.0001
Age	-0.8862	<.0001
FIM cognition on admission	0.0242	0.9414
FIM motor on admission	-2.4716	<.0001
Change in cognition score	1.0867	0.0289
Change in motor score	-1.4341	<.0001
RCI behaviour score	3.7364	.0973
Bladder continence status	-5.0363	0.3595

The estimate for the intercept indicates that the average hospital mean daily cost was $280.24. To illustrate the interpretation of the other estimates, take the FIM score on admission as an example. The estimated coefficient is –2.4716. This indicates that, if the values of all the other variables remain the same, but the FIM motor score increases by one point, the average change in the daily cost would be a decrease of $2.47.

From Table 31 it can be seen that the variables found to significantly contribute to the average daily cost of care were FIM motor score on admission, change in FIM motor score, change in FIM cognition score and age. When these variables were included, bladder continence status was found to be not significant. Including all seven variables in the model accounted for 34 per cent of the within hospital variation in daily cost.

What change in cost can be attributed to incontinence? From Table 30 it can be seen that the estimated coefficient for bladder continence status is –5.0363. It would appear that, if the values of all other variables were to stay the same, but the patient was incontinent rather than continent, the average daily cost of care would decrease by $5.04. This result doesn't seem logical. The reason it has happened

is that the continent group and the incontinent group are different in other ways. The average FIM motor score for continent patients is about 23 points higher than that for incontinent patients. Similarly, incontinent patients tend to be older and to differ from continent patients in other ways. The result of this is that, although we can use the model to compare the costs of patients who are the same in every respect except for their continence, in reality such patients are extremely rare. The effect of the incontinence is confounded with the effect of age and other functional impairments. Added to this is our uncertainty that we have only incontinent patients in the incontinent group. They all scored less than 7 on the bladder management item, but some of them would have been given this score because of mobility problems rather than incontinence.

To overcome this problem in a prospective data collection, there needs to be a specific data item indicating continence status. In addition, patients would need to be matched on all relevant variables other than continence status. The SNAP data set used in this analysis consists of only stroke patients undergoing rehabilitation. A prospective data collection should be designed to include a greater variety of patients, including those in acute as well as sub-acute care.

12.2.5.2 Impairment Group – Orthopaedics

The same analysis was repeated for orthopaedic patients, yielding similar results: see APPENDIX H – Subsidiary Tables and Figures for the SNAP study, Table 51, Table 52, Figure 20, Table 53.

12.3 Results of analysis for bowel incontinence patients

12.3.1 Descriptive Analysis by Case Type, Episode Type and Age

For the total dataset, 49 per cent of Rehabilitation patients and 55 per cent of GEM patients were classed as being bowel incontinent. These figures are slightly higher than for bladder incontinence, which probably occurred because the FIM score denotes people with constipation (who need nursing assistance) as being not totally independent (e.g. not score 7).

Of patients treated as inpatients, 60 per cent were denoted as bowel incontinent. The proportion is much lower for patients treated in an ambulatory setting, ranging from 19 per cent for outpatients, 29 per cent for same-day admissions, to 35 per cent for community patients. This result is not surprising as bowel incontinence could affect the choice of treatment setting.

Nine of the sixteen impairment groups contained more than 50 per cent of patients classified as bowel incontinent (compared with six groups for bladder incontinent, see Table 32). The two largest impairment groups, Orthopaedic Conditions and Stroke were both amongst these nine groups. The Stroke group had exactly the same proportion bowel incontinent as bladder incontinent (56 per cent) whereas in the Orthopaedic group, 51 per cent were bowel incontinent but only 43 per cent bladder incontinent.

Table 32 Percentage Bowel Incontinent by Impairment Group

Impairment Group	Percent Incontinent	No. in Impairment Group
Spinal Cord Dysfunction	79.4%	364
Debility	66.6%	515
Pulmonary	56.6%	357
Stroke	55.7%	1772
Congenital Deformities	54.5%	11
Burns	53.3%	15
Neurological Conditions	52.3%	585
Other Disabling Impairments	52.1%	503
Orthopaedic Conditions	51.3%	2561
Major Multiple Trauma	47.7%	86
Brain Dysfunction	46.5%	775
Developmental Disabilities	46.2%	13
Amputation Of Limb	44.4%	394
Cardiac	39.0%	420
Arthritis	32.5%	286

Pain	28.0%	761

As regards age, more than 70 per cent of the children under 10 were found to be bowel incontinent, but there were only 14 patients in this group. From the age of 30 onwards, the percentage of patients who are bowel incontinent tends to increase with age.

Table 33 Percentage Bowel Continent and Incontinent by Age Group

Age Group	Percentage Continent	Percentage Incontinent	Number in Age Group
0 – 9	28.6%	71.4%	14
10 – 19	63.3%	36.7%	128
20 – 29	61.0%	39.0%	331
30 – 39	66.0%	34.0%	429
40 – 49	65.2%	34.8%	572
50 – 59	63.3%	36.7%	668
60 – 69	55.8%	44.2%	1318
70 – 79	47.1%	52.9%	2796
80 – 89	40.3%	59.7%	2639
90 – 99	32.4%	67.6%	513
≥100	10.0%	90.0%	10
Overall	49.4%	50.6%	9418

The histograms for age distribution of bowel incontinence (total dataset and subgroups) are shown in APPENDIX H – Subsidiary Tables and Figures for the SNAP study, (Figure 26. Bowel Continence/ Incontinence by Age Group – Outpatients). These show similar patterns to those found in bladder incontinence.

12.3.2 Relationship of continence to discharge destination

The "reason for the completion of the episode of care" was collected as a data item in the SNAP Study in relation to bowel continence status. Categories of response are summarised in Table 34 below.

Table 34 Discharge Destination for Inpatient Episodes, Bowel Incontinence

End Reason	Percent of Continent Group	Percent of Incontinent Group
Discharged to nursing home	3.9%	12.6%
Discharged home	82.3%	59.6%
Died	0.5%	2.9%
Continued in care after episode end	7.8%	15.2%
Discharged at own risk	0.8%	0.7%
Statistical discharge from leave	0.2%	0.1%
Episode incomplete at end of data collection	4.4%	8.8%

While more than 82 per cent of patients with no continence problem were discharged home at the end of their episode, this was true for only 59 per cent of the incontinent group. Instead, those with an incontinence condition were more likely to go to a nursing home or to move on to further care. They were also more likely to still be in care when data collection ceased, reflecting a longer average length of stay. Of course, other differences between the two groups (age and other FIM scores) would contribute to this finding. There is no suggestion that incontinence alone would result in these differences.

12.3.3 Results for Bowel Incontinence – Average Length of Stay (LOS) and

Average Daily Costs

The average daily cost and length of stay for each Case Type/Episode Type subgroup for both bowel continent and incontinent patients are presented in Table 35 below.

Table 35 Average Daily Cost and Length of Stay for Subgroups of Bowel Incontinence

Case Type	Episode Type	Bowel Continence Status	Number of Episodes	Average LOS	Average Cost Per Day	p-value for diff in cost
Rehabilitation	Inpatients	Continent	2435	20.8	$242	**<0.001**
		Incontinent	3225	27.6	$268	
	Same Day	Continent	220	41.3	$121	**<0.002**
		Incontinent	95	32.0	$158	
	Outpatients	Continent	801	52.0	$71	0.365
		Incontinent	184	41.7	$75	
	Community	Continent	247	63.1	$76	0.698
		Incontinent	83	65.2	$79	
GEM	Inpatients	Continent	306	17.0	$160	**<0.001**
		Incontinent	807	19.3	$199	
	Same Day	Continent	96	55.3	$92	0.372
		Incontinent	32	54.9	$98	
	Outpatients	Continent	19	81.6	$63	0.063
		Incontinent	10	44.7	$86	
	Community	Continent	526	56.3	$73	0.131
		Incontinent	332	70.9	$69	
Overall			9418	31.3	$199	

* Difference is statistically significant at 5 per cent level

Within each Case Type/Episode Type subgroup, the average daily cost for the bowel incontinent group is generally higher than for the continent group. The average LOS on the other hand is quite variable. Statistically significant differences were found in the overnight admitted and same-day admitted rehabilitation groups as well as in the overnight admitted GEM group ($p<0.01$ for these three groups). For each of these three groups the daily cost of caring for an incontinent patient was generally higher than the daily cost of caring for a continent patient.

12.3.4 Cost of Incontinence in specific impairment groups

As for bladder management, the aim of this part of the analysis was to:

1. Establish whether daily costs of patients with bowel incontinence are higher than those of who are bowel continent,
2. Identify variables that contribute to the daily cost of treatment, and
3. Investigate the increased cost that can be attributed to bowel incontinence, if possible.

12.3.4.1 Impairment Group – Stroke

Table 36 shows the per diem costs for bowel continent and bowel incontinent patients with stroke impairment.

Table 36 T-Test for Difference between Means for Stroke Patients

Case Type	Episode Type	Bowel Continence Status	Number of Episodes	Average Per Diem Cost	p-value for t-test
Rehabilitation	Inpatients	Continent	432	$269.23	.032*
		Incontinent	765	$283.57	

	Same Day	Continent	70	$128.11	.652
		Incontinent	39	$134.23	
	Outpatients	Continent	136	$82.46	.783
		Incontinent	41	$84.67	
	Community	Continent	43	$96.66	.174
		Incontinent	19	$78.06	
GEM	Inpatients	Continent	6	$174.50	.168
		Incontinent	65	$235.03	
	Same Day	Continent	39	$88.82	.246
		Incontinent	14	$99.16	
	Outpatients	Continent	6	$77.40	.970
		Incontinent	3	$76.44	
	Community	Continent	53	$69.55	.874
		Incontinent	41	$70.60	
Overall			1772	$223.60	

* Difference is statistically significant at 5 per cent level

For inpatient rehabilitation patients, the average daily costs were found to be significantly different between the bowel continent ($269 per day) and the incontinent groups ($283 per day). Within some other stroke subgroups, bowel continent patients had higher daily costs but small sample sizes meant that the difference was not found to be statistically significant.

Which variables contribute to the overall cost of treatment? The same correlations amongst the variables thought to be relevant to the cost of treatment were calculated as for bladder incontinence (12.2.5.1). Correlations between these variables and average cost per day were also calculated (refer Table 37 below, Spearman correlations between continence status and all other variables, Pearson Correlations calculated between all other pairs of variables).

Table 37 Correlations between pairs of variables relevant to cost

	Cost per day	Age	Cognition Score	Motor score	Cognition change	Motor change	RCI behaviour	Bowel Continence status
Cost per day	1	-.146	-.197	-.250	.031	-.060	.088	.020
Age	-.146	1	.000	-.089	-.119	-.127	-.019	.140
Cog Score	-.197	.000	1	.486	-.416	.028	-.189	-.343
Motor score	-.250	-.089	.486	1	-.078	-.238	-.118	-.555
Cog change	.031	-.119	-.416	-.078	1	.451	.031	.058
Motor change	-.060	-.127	.028	-.238	.451	1	.007	.091
RCI behaviour	.088	-.019	-.189	-.118	.031	.007	1	.107
Bowel Continence status*	.020	.140	-.343	-.555	.058	.091	.107	1

* Continence status (Cont status) was scored as 0 representing continent and 1 representing incontinent

Most of these correlations were discussed in the previous section on bladder incontinence. Only the Spearman correlations between bowel continence status and the other variables have not been discussed. However, the pattern of correlations is similar to that found in the correlations with bladder continence status. The highest in absolute value is that with FIM score on admission. The discussion

relating to the corresponding bladder continence status correlation is also relevant here. Please refer to the previous section.

The next step in the analysis was to model the cost per day using a combination of the other variables. Again, a multilevel model was fitted, incorporating age, FIM cognitive score on admission (total of FIM items 14 – 18), FIM motor score on admission (total of items 1 – 13), change in FIM cognition score from beginning to end of the episode of care, change in FIM motor score from beginning to end of the episode of care, and RCI behaviour total as well as continence status as explanatory status. The response variable was the average daily cost of care. The resulting coefficients and their p-values are presented in Table 38.

Table 38 Estimated coefficients from multilevel analysis

Variable	Estimated coefficient	p-value
Intercept	280.24	<.0001
Age	-0.8881	<.0001
FIM cognition on admission	0.0320	0.9224
FIM motor on admission	-2.4633	<.0001
Change in cognition score	1.0714	0.0315
Change in motor score	-1.4263	<.0001
RCI behaviour score	3.8196	.0899
Bladder continence status	-4.8456	0.3635

The estimate for the intercept indicates that the average hospital mean daily cost was $280.24. To illustrate the interpretation of the other estimates, take the FIM score on admission as an example. The estimated coefficient is –2.4633. If the values of all other variables remain the same, but the FIM motor score increases by one point, the average change in daily cost would be a decrease of $2.46.

The results for bowel incontinence were found to be very similar to those for bladder incontinence. Table 38 shows that the variables found to significantly contribute to the average daily cost of care were FIM motor score on admission, change in FIM motor score, and change in FIM cognition score and age. When these variables were included, bowel continence status was found to be not significant. Including all seven variables in the model accounted for 34 per cent of the within site variation in daily cost.

What change in cost can be attributed to incontinence? From Table 38 we see that the estimated coefficient for bowel continence status is –4.8456. If the values of all other variables were to stay the same, but the patient was incontinent rather than continent, the average daily cost of care would decrease by $4.85. As for bladder management, this result doesn't seem logical. The reason it has happened is that the continent group and the incontinent group are different in other ways. The average FIM motor score for bowel continent patients is about 23 points higher than that for incontinent patients. Similarly, incontinent patients tend to be older and to differ from continent patients in other ways. The result is that, although we can use the model to compare the costs of patients who are the same in every respect except for their continence, in reality such patients are very rare. The effect of the incontinence is confounded with the effect of age and other functional impairments. Added to this is our uncertainty that we have only incontinent patients in the incontinent group. They all scored less than 7 on the bowel management item, but some of them would have been given this score because of mobility problems rather than incontinence.

Again we recommend that to overcome this problem in a prospective data collection, there needs to be a specific data item indicating continence status. In addition, patients need to be matched on all relevant variables other than continence status. The SNAP data set used in this analysis consists of only stroke patients undergoing rehabilitation. A prospective data collection should be designed to include a greater variety of patients, including those in acute as well as sub-acute care.

12.3.4.2 Impairment Group – Orthopaedics

The same analysis was undertaken for orthopaedic patients, yielding very similar results (Table 54, Table 55, and Table 56, Appendix H).

12.4 Summary of costing analysis results and Discussion

The average daily costs of incontinent patients were consistently higher than the average daily costs for continent patients. However, the difference was statistically significant only for inpatients, because of smaller sample sizes in many of the ambulatory care episodes.

The analysis to determine which variables contributed to the overall cost of the episode of care consistently demonstrated that the FIM motor score on admission had the largest correlation value with cost per day. The negative relationship between these variables indicates that as motor scores increase, the cost per day decreases. The correlation between the continence status and the cost per day was fairly low for each of the sub-groups, although the correlation between continence status and FIM motor score on admission was consistently one of the highest correlations. This is likely to reflect the fact that patients who are incontinent often have other functional impairments as well.

The results of the multilevel analysis demonstrated that the "continence status" variable was negative, indicating that if the values of all other variables were to stay the same, but the patient was incontinent rather than continent, the average daily cost of care would decrease. This result seems counter-intuitive and further analysis would be required to explain this finding.

One of the main areas for discussion from this analysis arises from the definition of incontinence we have used. The definition was determined by one of the authors (K. Moore) reviewing the definitions provided in the UDS FIM™ manual for each of the 7 possible scores for the two relevant FIM items – bladder management and bowel management. It was determined that from a clinician's perspective (KM), the only score which could be classified as continent was 7 (complete independence). For each of the other possible scores (1-6) some assistance was required for bladder and bowel management and these scores were therefore classified as incontinent.

The authors were advised that in some cases, patients may be scored a 5 for bladder management where they were immobile and require a bed pan, although they were likely to be considered continent. The authors are also aware that some patients may be scored as 1- 6 for bowel management where they are considered to have faecal impaction rather than incontinence. However, the retrospective nature of this analysis meant that the authors were required to make assumptions about the definition of incontinence. Given that we were interested in determining the additional costs associated with incontinence compared to continence, only patients scoring a 7 were considered to be continent, due to the additional resources required to provide care for patients scoring 1- 6 for bladder and/or bowel management. It is acknowledged that this definition is likely to lead to inflated incidence levels and affect the current costing analysis. Thus it is recommended that future studies aiming to analyse costs associated with incontinence should collect continence status prospectively. Further, future retrospective analysis of the SNAP data set to evaluate the additional costs associated with incontinence should include some sensitivity analysis around the definition of incontinence and the effect the cut-off has on the costing analysis e.g. use a cut-off of 5 for bowel management.

For many aspects of the analysis, the results showed a statistically significant difference between the costs associated with incontinent and continent patients for inpatients only. This suggests that future research in this area should concentrate on inpatients, as analysis of ambulatory patients for this study question may not be as useful.

Using the measurement of continence status at the beginning and the end of the episode of care, it was interesting to track the movement between these two classifications for bladder management. While the large majority of patients maintained their continence status at the beginning and the end of the episodes of care, it was heartening to note that there were groups of patients (particularly rehabilitation patients) who changed their status from incontinent to continent. This is an important finding of this study given the significant cost differences associated with continent and incontinent patients.

This analysis also highlighted the usefulness of multilevel analysis to account for the large amount of variation between average daily costs of care at the different facilities represented in the database. This variation went from an average daily cost of $200 to $500. It is important to account for these differences in any model that aims to measure differences in cost.

In retrospect, the costing methodology of the original SNAP study may have been suboptimal, in that "other non-core costs" were not used in the analyses. These "other non-core costs" included medical costs. Inpatients with urinary and/or faecal incontinence may have required specialist assessment by urologists, urogynaecologists, or colorectal surgeons. Because medical costs were not included in the analysis, such specialist assessments would not have been included in the cost data collection at all.

Readers should be aware that the current SNAP study represents the first effort to use this 1996 database to analyse costs for any specific condition. Hence although it appears that SNAP data is not useful for future economic analysis of incontinence, this is an important and original negative finding.

Section 13. Substudy 7: Analysis of the Relationship Between Functional Independence Measure and Definitions of Incontinence

13.1 Background

As discussed in Appendix J any future data collection on the costs of incontinence will need to address the question of the definition of incontinence. In Substudy 7 of the AN-SNAP database analysis where incontinence was defined as a FIM score less than 7, there was considerable discussion on whether this was an appropriate level to set the definition at, particularly as patients with FIM scores of 5 are given that score because of immobility (requiring assistance, for example, with a bed pan) rather than incontinence. The question arose as to whether it would be better to set the FIM score of less than 5 to 6 corresponding to incontinence, rather than 7.

13.2 Method

In order to study the relationship of the FIM score for clinically documented urinary or faecal incontinence, the FIM Motor scores for bladder and bowel management were collected for 27 incontinent patients included in Substudy 1 at Sutherland and Port Kembla Hospitals. These patients were clinically assessed as being incontinent by nursing staff on admission and were recorded as incontinent in the nursing care plans. The medical records were retrieved and the FIM Bladder and Bowel Management Scores on admission and on discharge were noted.

13.3 Results

Table 39 indicates that, of the eight patients from Sutherland Hospital (only patients admitted to Killara Ward were given FIM scores) with FIM Motor scores, only four had complete records of scores taken at the beginning and end of their hospital admission. FIM Motor Scores for bladder and bowel management were collected from 19 patients in Port Kembla Hospital out of the total of 24 from Substudy 1.

Table 39 FIM Motor Scores for Incontinent Patients

Patient ID	FIM Bladder Management		FIM Bowel Management	
	Beginning	End	Beginning	End
SUK02	1	1	1	1
SUK03	1	Unknown[a]	1	Unknown[a]
SUK04	2	2	6	2
SUK05	4	4	4	4
SUK06	2	Unknown[b]	3	Unknown[b]
SUK07	1	1	3	3
SUK08	2	Unknown[a]	3	Unknown[a]
SUK09	1	Unknown[b]	1	Unknown[b]
PK01	4	5	4	6
PK02	2	1	2	1
PK03	4	6	5	6
PK04	4	4	4	4
PK05	1	6	1	6
PK06	1	1	1	1
PK07	2	1	1	1
PK08	6	1	5	6
PK09	6	6	6	7

PK10	6	6	7	7
PK11	2	2	2	2
PK12	2	7	2	6
PK13	1	6	1	6
PK14	3	1	3	1
PK15	1	1	1	1
PK16	1	Unknown[a]	1	Unknown[a]
PK17	6	Unknown[a]	7	Unknown[a]
PK18	1	1	1	1
PK19	1	1	1	2

[a] The FIM Motor score was not assessed or recorded in the medical records.

[b] The FIM Motor score at the end of the admission not recorded because the patients were still in hospital at the completion of the study.

Figure 10 FIM bladder management admission score by number of incontinent patients

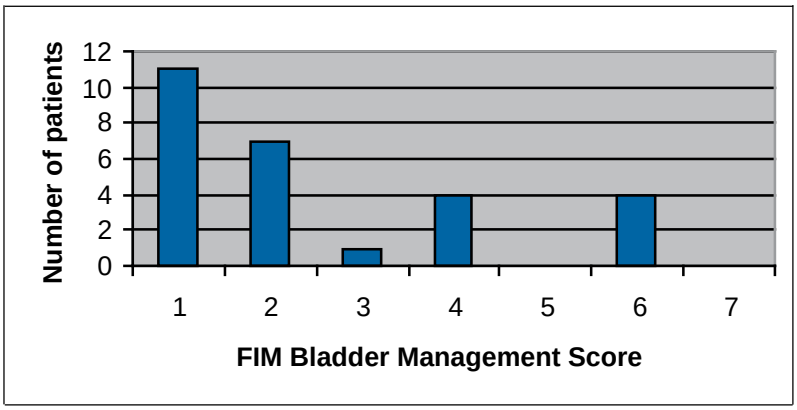


Figure 10 shows that 23 out of the 27 patients (85 per cent) which were assessed in nursing care plans in Substudy 1 as having urinary incontinence, had FIM Bladder Management Scores of 4 or less. However, the remaining 4 out of 27 patients (15 per cent) had a FIM Bladder Management Score of 6.

Figure 11 FIM bowel management admission score by number of incontinent patients

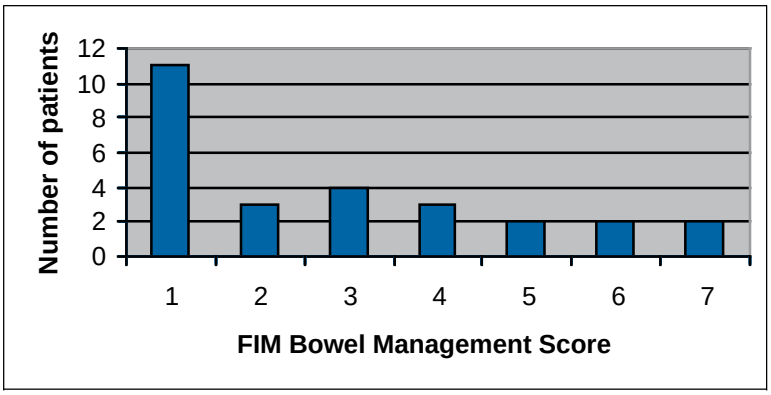


Figure 11 shows that 25 out of the 27 patients assessed as incontinent in the nursing care plans had FIM Bowel Management Scores of 6 or less. Surprisingly, 2 patients had scores of 7 (complete independence).

13.4 Conclusion

If the extensive AN-SNAP database is to be of use to gather information on the resource utilisation of patients with continence conditions, one of the preliminary questions that needs to be addressed is how bladder and bowel incontinence are defined in order to retrieve the necessary data on incontinent

patients receiving sub-acute and non-acute care. Most of the patients from Substudy 1 with incontinence defined as bladder and/or bowel leakage on more than one occasion over two consecutive days, had FIM Motor scores of 4 or less. There were, however, 10 patients with FIM scores of 5 or more which suggests that in a prospective data collection, FIM scores cannot be relied on as the basis for flagging incontinence. While this pilot study is small, it indicates that specific data items signifying urinary and bowel incontinence are needed.

Section 14. Substudy 8: Study of The Prevalence of Incontinence in The Acute Care Setting

14.1 Method

A survey of all inpatients in St. George Hospital was conducted over an eight hour period in February 2002. In this substudy, five project team members visited all wards with the exception of the Intensive Care Unit, Accident and Emergency and Outpatients. The study methodology was approved by the Ethics Committees of South Eastern Sydney Area Health Service and the University of New South Wales.

Patient's age, sex and the ward speciality were recorded. The patients were asked for informed consent to participate in the survey. Two questions pertaining to incontinence were asked:

1. Do you consider yourself to have a bladder problem that involves the leakage of water or urine?

2. Do you ever wear a pad or tissues for protection?

14.2 Results

Table 40 Age, sex and continence status of hospital inpatients

Ward specialty	Gender	No. of patients	No. absent	Unable to answer	No. incontinent (per cent)
Rehabilitation	F = 11, M = 11	22	3	0	9 (47%)
Antenatal	F = 12	12	0	0	5 (41%)
Cardiac Medical	F = 9 M = 16	25	6	1	5 (28%)
Neurology	F = 17 M = 9	26	3	8	9 (60%)
Respiratory	F = 12 M = 12	24	9	1	4 (28%)
Aged Care	F = 13 M = 11	24	1	9	4 (28%)
Surgical (GIT)	F = 18 M = 11	29	0	1	5 (17%)
Renal	F = 12 M = 12	24	6	1	3 (17%)
Vascular/ Endocrine	F = 9 M = 13	22	3	0	3 (15%)
Oncology	F = 14 M = 13	27	2	3	3 (13%)
Postnatal	F = 11	11	0	0	1 (9%)
Ear Nose Throat	F = 8 M = 11	19	3	2	1 (7%)
Orthopaedics	F = 17 M = 13	30	0	6	0 (0%)
Cardiothoracic Surgical	F = 7 M = 5	12	3	2	0
Urology	F = 5 M = 9	14	5	0	0
Day Surgery	F = 1 M = 1	2	0	0	0
TOTAL		333	44	34	52

Table 40 shows that there were 333 inpatients at St. George Hospital on the day of the survey. Of these, 297 patients participated in the survey with 52 patients answering in the affirmative to both or either of the survey questions. Thus 17.5 percent of the admitted patients in St. George Hospital were incontinent as reported by the patients themselves. Although approximately half of the patients in the Rehabilitation and Antenatal Wards at St. George Hospital reported incontinence, most of the incontinent patients (36 per cent of the total incontinent inpatients at St. George Hospital) were located in the Rehabilitation and Neurology Wards, as expected.

There were 28 patients who used pads out of the 52 who said they were incontinent (54 per cent wore pads and reported incontinence). Thus, 46 per cent of the patients with incontinence did not use pads. By definition, they had urinary leakage but it was not a hygienic problem, thus they did not fit into the strict ICS (prior to 2002) definition of incontinence. They are the only patients in this study who represent "patients at risk of developing incontinence". Patients at risk are almost impossible to capture, and the tender specifications were somewhat ambitious in asking us to seek them out, as they do not come to attention other than by a census such as in Substudy 7.

14.3 Discussion

So far as could be determined from the literature review, this substudy represents the first attempt to conduct a census of urinary leakage at a major acute hospital in the world. The fact that 17 per cent of patients admitted to urinary leakage was surprising especially because none of the patients in the urology ward, and only 5/12 of those in the antenatal ward (41 per cent) and 1/11 of those in the postnatal ward (9 per cent) answered affirmatively.

Only 54 per cent of those with urinary leakage wore pads, so the remaining 46 per cent represent a chance to "capture" patients at risk of developing worsening incontinence that leads them to wear pads in the future. In a sense, they have "pre-clinical" incontinence in that they do not have a "hygiene problem". Screening these patients and offering early intervention would be a useful endeavour, especially if it were undertaken as an RCT.

Section 15. Conclusions from the second report

15.1 Overview

In the seven interrelated pilot substudies presented in this Second Progress Report, it is clear although patient level costing studies have the capability of yielding accurate cost and utilisation data; the reliability of the information is highly dependent on intensive on-site training and support. The benefits of such detailed information must be weighed against the demands on the time of the staff and the timeliness of the data collection.

Having concluded the pilot studies and analysed the cost data, some general conclusions can be reached.

The patient-level costing ("bottom-up" data) showed highly variable costs for incontinence care in the different settings. This was to be expected, as the type of patients, and the intensity of nursing or medical care, varied a great deal between these care settings. The "take home message" is that economic studies are very dependant upon the setting in which they are conducted. The design of future field trials will have to incorporate this finding. That is, it will not be possible to undertake just one or two large studies in one or two care settings in order to derive the economic costs of incontinence for Australia as a whole. As was discussed in the Stakeholder's Meeting, urinary and/or faecal incontinence affects patients in a vast array of care settings across the entire health care system.

15.2 Deficiencies and Methodological Problems

In retrospect, there were deficiencies and method problems in each of the studies. These were as follows:

A. In the chronic/subacute care settings of patient level costing, the data collected at Port Kembla Hospital could not be analysed because so much of the data was missing. This occurred because of a lack of pre-existing research infrastructure at this busy hospital. The research staff from UNSW made several visits to the site but could not influence the day-to-day collection of the data at the bedside.

B. In the Nursing Hostel Villages, it was hoped to supplement the blue sheet data with collection of DBICI data. Very few patients were willing to complete this questionnaire because of the questions about income level. The DBICI is a useful data collection tool, with published test-retest reliability, construct validity and sensitivity to change for ambulatory women. In future studies, patients should be approached more carefully and the information should be recorded anonymously, or else the income information should be abandoned. The same applies to community dwelling women interviewed at home.

C. In the Pelvic Floor Unit outpatient setting, routine clinic staff found the DBICI too time consuming. Medical staff, who had little knowledge of continence pads, found it irksome and difficult to complete. The DBICI should be completed by a trained NCA who is paid to conduct this study as a research task. It cannot be made part of ordinary clinical duties.

D. A major deficit of the studies was the failure to include women aged 40-65, i.e. not childbearing and not elderly. This a major group of incontinence sufferers, who were not included in these pilot studies because they were not included in the Tender specifications.

E. With respect to the acute inpatients that were seen by Nurse Continence Advisors on the wards of St. George Hospital, one aspect of their "cost" of incontinence has not yet been captured. Anecdotally, the continence advisors have indicated that they are sometimes called to see a patient who is in hospital for a non-incontinence diagnosis, but are then found to be incontinent by the ward nurses. After assessment by the continence advisor, and when the patient is nearing readiness for discharge, the family then announces that they do not feel able to care for the patient at home anymore, partly because of their urinary or faecal incontinence. The patient is then put on a waiting list for a nursing home or hostel placement, and this can result in a prolonged Length of Stay. Often the episode of care is then re-coded into the SNAP category, e.g. an "episode type change" is made. The project team was not able to discover a method whereby this phenomenon can be captured.

F. As was expected, the small sample sizes meant that most of these pilot studies are not suitable for peer-reviewed publication as the variability of the sample data may not represent the true variability of the data. Of course the purpose of the pilot studies was to assess the feasibility of the data collection methods so the aim was achieved.

G. As regards the retrospective casemix data used in the SNAP study, the following points should be reiterated:

i. Despite our finding that the majority of patients with significant bladder or bowel incontinence did have a FIM score of five or less, we have some concerns about the definition of "incontinence" within the FIM sore. As regards bladder incontinence, our previously mentioned concern about those patients who are continent with the aid of an indwelling catheter remains. As regards bowel incontinence, the wording of the FIM score assessment algorithm appears to focus upon patients needing help with constipation, faecal impaction and overflow incontinence. This would fit in with the very high prevalence of bowel incontinence seen in the data presented, which is at variance with the prevalence of faecal incontinence in the general literature.

ii. Many of the analyses were only significant for incontinent/not incontinent when studied in the "overnight stay", i.e. hospital inpatients. Not surprisingly, the outpatients and day-only patients were much less likely to be incontinent. Therefore future analysis of the subacute care data, in the proposed field trials, might be best confined to the inpatient group.

iii. An overwhelming result was found regarding the cost differential for patients who came into the facility incontinent and went out continent, compared to those who came in and went out still incontinent. A large cost was also seen in the worst case scenario of patients who were admitted continent but were discharged incontinent. The cost differential for these patients was highly significant, indicating that retrospective analysis of the SNAP data for this parameter is informative regarding the cost of incontinence to the health care system.

iv. The effect of the variation from differing costs of care between different hospitals (ranging from $200 per day to $500 per day) could have provided a large confounding effect. Fortunately, our statistical technique included multiple hierarchical analyses that allowed this confounding effect to be detected and accommodated. Obviously this is an important factor to be considered in future analyses.

H. As regards the casemix modelling exercises, the authors were surprised to find that, within the current costing for DRGs, incontinence seldom had any impact upon the cost weight or the length of stay. Hence the current collection of data for Casemix is not useful to assess treatments for incontinence in the acute care setting.

I. The general framework for the pilot studies reported to date is that of the "cost" to the health care system, not including the sample of patients undergoing Dowell-Bryant Incontinence Cost Index surveys, for which the personal costs for treatment and consumables were obtained. This deficit needs to be rectified in future Field Trials. Most of the pilot studies focussed on either the "system" costs of caring for incontinence, or the "personal" costs of incontinence care, but did not include both in the one study. For example, patients in subacute care at Sutherland ("Blue Sheet" bedside study) were only followed for 21 days of inpatient care. Had they been followed home after discharge, their "personal" incontinence costs would have emerged, providing a much better picture of the overall costs of such patients (but much greater funding would be needed for this type of study).

15.3 Overhead Costs

The "overhead costs" for the various pilot studies were seldom measured. For example, the "White Card" study of acute inpatients did not consider the overhead costs of their inpatient stay. This would have required a control group of similar patients, with no incontinence, for comparison. The retrospective SNAP study did include some overhead costs in the original framework of the SNAP data collection (e.g. pharmacy, allied health) and the overall costs of incontinent patients were significantly greater than the non-incontinent patients in this study. So overhead costing is an important factor that will need to be a measured (or accurately estimated) in future field studies.

15.4 Burden of Disease

Finally, at this stage, the Project Team had an overall sense that our measurement of the Burden of Disease, for both urinary and faecal incontinence, will not be adequate. Part of this anticipated inadequacy related to the fact that, at the time of writing, the Project One Team had not indicated what Quality of Life measures should be included in the analysis. Obviously, an important part of any framework for the estimation of the cost of a given condition will be the calculation of QALYs, so as to provide objective yardstick measures of the economic value of continence treatments (or lack thereof). Such an outcome measure has subsequently been specified by the Outcome Measurement Suite (Project One) team.

However, such technical issues are not the heart of the matter. Following the discussion of Burden of Disease, undertaken by Dr Terri Jackson at the morning session of the Stakeholders' meeting (refer Appendix J), the Project Team has an overall impression that the pilot studies to date do not measure the overall burden of the disease of incontinence in the entire community.

There are a number of key issues relating to each patient subgroup. These are discussed in turn in the following section.

For women of childbearing age, it is known that approximately 30 per cent suffer from some mild leakage in the postpartum period, which undergoes some spontaneous resolution. However, some of these post-partum women continue to suffer in silence for many years before seeking help. They fall in to the group of "patients at risk" to some extent, because they have not found their incontinence to be of sufficient social or hygienic problem to lead them to come forward for help. Yet if some of these women develop obesity or constipation in the following decade, their incontinence will be likely to surface in the health care system. A longitudinal study of postnatal women over 30-40 years would be needed to fully understand this problem.

As regards the patients with incontinence of neurological origin, similar problems apply. Although the relationship between stroke and urge incontinence is clear, we do not know how many patients with stroke go home with mild incontinence and suffer from it for some time before asking for help.

As regards the patients in the elderly, frail elderly and dementia subgroups, the case histories of Caroline Dowell suggest that many suffer a great deal and may be housebound by their incontinence. Many elderly, frail or mildly demented patients (who are not easily categorised into the columns of the present report) live at home and are not effectively captured by the reported pilot studies. The four case histories from Ms Dowell however do indicate large personal expenditure upon the problem, a major curtailment of social activities by those affected and considerable concern by families and general practitioners. In five to ten years, such patients may consume even greater resources. Information from the Private Nursing Services may shed light on this subject, but would require a prospective study.

In conclusion, these preliminary reflections upon the data in this project indicate that although much of what has been collected is accurate and meaningful, a portion of the Burden of Disease has probably not yet been captured. The traditional standard for economic analysis, that of a societal perspective, is perhaps not yet possible, but certainly a measure of the costs to the health care system in providing management of incontinence is available from the present data. As explained in the literature review, one must distinguish between the costs of management of incontinence, and the considerably larger costs of incontinence itself.

Third Progress Report

Section 16. National and International Gaps

This third report provides an overview of currently available methods to measure cost of incontinence. It also identifies gaps in both national and international information in the continence field. Approaches to economic evaluation and related data collection that may be feasible in any subsequent field trials are recommended.

16.1 Summary of Suggestions for Future Field Studies based on Literature Review and Pilot Study Experience

The literature review presented in the First Report of the Project indicated that the following economic areas were under represented in the presently available literature:

1. Faecal incontinence (only 15 per cent of all studies)
2. The frail elderly (only 12 per cent of studies)
3. Male incontinence (only 5 per cent of studies, all post prostatectomy)
4. Severe neurological incontinence (Multiple sclerosis, spina bifida, spinal injury, only 1 study of each)
5. Continence management for culturally diverse people and aboriginal people – nil published
6. Younger women of childbearing age – no economic data
7. Prevention programmes aimed at people at risk of incontinence – no economic data

The pilot studies presented in the Second Report include cost data about some of these deficient areas:

1. Faecal incontinence in frail elderly and acute hospital inpatients

2. 3. Male incontinence in the frail elderly

4. Severe neurological incontinence in sub-acute care

6. A sample of young women of childbearing age was costed in the acute hospital

7. A one-day survey of an acute hospital was also undertaken, to measure the percentage of acute inpatients that leak urine but are hospitalized for other reasons. Such patients provide one avenue for accessing those who are "at risk" of incontinence, in whom early treatment could prevent clinical incontinence emerging.

However, these pilot studies do not provide a complete picture, but may inform future studies. The literature review also identified further specific gaps not considered in the Pilot Studies. These do not comprise formal economic analyses, but would provide useful information toward economic analysis in the future.

Some of these specific gaps in our knowledge are as follows:

1. As regards the frequency and type of surgical procedures for stress incontinence, the Australian National Hospital Data Collection (ANHDC) could be used to determine the absolute number and per capita frequency of operations being done for this condition in Australia. The Institute of Health and Welfare Annual Reports provide this information but it has never been collated. Such a retrospective review of the incidence of continence operations in Australia would provide useful economic data about the magnitude of State Government expenditure on stress incontinence, and whether it is increasing as the median age of the population is rising (over the last 10-20 years). Such data would provide useful justification for enhanced expenditure on outpatient-based conservative therapy for mild incontinence, which can be cured in 65 per cent of cases.

   As regards the burden of disease of Faecal Incontinence, such a survey of ANHDC data would also be informative, although it would not provide support for cheaper conservative therapy (because as yet there is no data to show that conservative therapy is as effective as surgery for mild cases of faecal incontinence). Some current projects that are being undertaken by AIHW are also examining data sources, prevalence estimates and burden of illness considerations for incontinence.

2. The whole issue of the direct costs of patients' management of faecal incontinence, and costs of operations for faecal incontinence, and their effectiveness, is completely under-researched. For example:

   a) The DBICI (a nurse administered questionnaire regarding the costs of urinary incontinence) could be easily applied to faecal incontinence.

   b) The acute hospital costs of operations for faecal incontinence could be obtained from the ANHDC

   c) The efficacy of surgery for faecal incontinence and the cost effectiveness of such procedures (as opposed to "do nothing" observation of the natural history) does not appear to have been investigated from an economic perspective.

After completing the pilot studies contained in the Second Progress Report, further appropriate studies have been identified, refer Section 16.4. The funding body (e.g. Commonwealth Government) would obviously need to decide which of these research questions and economic issues are the most important from their perspective. A scoring system has been developed to prioritise these possible studies, based on clinical and economic value (see 16.3). Further economic and outcome-based field trials would then need to be undertaken before data can be incorporated into microeconomic and macroeconomic frameworks with some degree of confidence.

The proposed field trials should be structured to have a sound economic framework. That is, they should follow a structure of cost effectiveness analysis or cost utility analysis, since cost of illness studies and cost minimization studies are not suitable for true economic analysis. The field trials should be designed with sufficient power to ensure that economic and clinical outcomes are rigorous and easily generalised. It is known from the work undertaken in this project that sufficient funding is essential to pay for adequate staffing: project staff are needed as well as payment for backfilling of these staff who are sufficiently knowledgeable to conduct the studies but who already have fulltime clinical and/or academic commitments.

16.2 Methods of Economic Analysis in the field of Incontinence

The three main economic questions arising in continence management are:

1. Is the management of incontinence appropriate? Are resources being used to treat patients inappropriately? Could incontinence management be more cost effective?
2. The costs of care and admission to nursing homes of patients with incontinence are obviously a major policy issue gaining increasing attention. What are the main cost factors and who bears the costs?
3. What are the distributional effects and issues of equity and access in the present methods of funding services and aids for incontinence?

There are obviously many possible clinical interventions across different patient groups in various care settings. One useful approach to forming a framework for the economic evaluations of continence conditions is derived in this project from the Health Benefit and Resource Group work coming from the UK and used more recently by Segal (2001) in Australia. This method uses a matrix approach to identify various patient subgroups, interventions, cost items and outcomes for various condition stages. For continence conditions, the matrix can be populated for the following condition stages:

- At risk of developing incontinence
- Identification of early stage incontinence
- Acute care of incontinence
- Chronic care of incontinence

Table 41 shows a matrix for continence conditions showing the condition stages, the patient subgroups in this project, the care settings for incontinent patients, and the cost items in incontinence care/ treatment and outcome measures. For example, in this table women at risk of developing incontinence could be the subject of a randomised controlled trial and receive either physiotherapy training or simple education to prevent incontinence whilst in hospital. The administration of the DBICI questionnaire with DRG based costs of hospitalisation can be used to elicit direct and personal costs. Cost Minimisation Analysis (CMA) assumes that the two interventions have identical outcomes (outcome measurement is thus not required) and therefore simply selects the cheapest. The row below shows that Cost Effectiveness Analysis (CEA) looks at different outcomes of two interventions using the frequency volume chart, pad test and quality of life measures allied to the same cost items. Cost Utility Analysis

(CUA) evaluates different interventions using health preferences or utility measures such as willingness to pay or quality-adjusted life year (QALY).

By populating a matrix of this kind with studies from Australia and overseas (both existing and new studies), a number of different economic and cost evaluations are possible. Using the elements in this matrix, the capacity to frame an economic evaluation and develop a notion of what constitutes "best buys" can be progressively developed. Decisions can then be made regarding the relative investment in preventive and curative interventions.

The priority questions forming the basis of field trials for outcomes and cost measurements in Project 3 need to be guided by the burden of disease borne by different patient groups, as discussed at the Project 2 stakeholders' meeting held on 29 October 2001 (refer Appendix J). This discussion revealed that about 15 per cent of the incontinent population have chronic intractable incontinence associated with neurological disease and longstanding incontinence which is managed but not cured. Approximately 20–25 per cent of incontinent patients are elderly or those with dementia, living at home or in nursing homes. While 50 per cent of nursing home patients are incontinent, they only account for approximately only 10 per cent of elderly patients and have a relatively short life span in the nursing home. About 30-40 per cent of women are incontinent after childbirth but this may resolve spontaneously in at least 10 per cent of these, unless women are obese and have no treatment. Men and women at risk of incontinence, estimated to comprise about 20 per cent of the total sample, remain an unknown and unreported group with a possibility for preventive treatment or early intervention.

Overall, the biggest group is incontinent women of reproductive and premenopausal age who often have multiple treatments and are amenable to cure. The next largest group is that of men and women at risk, followed by elderly and demented patients with incontinence that are not cured but have multiple co-morbidities and die earlier. The smallest group are those with neurological incontinence suffering many years of incontinence with little possibility of cure. Possible economic evaluations for continent conditions taking the relative burden of disease and treatment/management options into account amongst these patient sub-groups will now be discussed.

16.3 Essential steps for economic evaluation

As explained previously, Cost of Illness studies are not regarded as true economic analyses, because they do not weight the costs and benefits of different treatments, in fact they don't even measure the benefit derived from any treatment. Hence Cost of Illness studies are not considered in this section, although the Commonwealth Government may find them useful to just gauge the magnitude of incontinence costs (hence they were shown in the Matrix).

Criteria for economic evaluation studies: The decision to undertake an economic evaluation study should be guided by considering the following criteria in turn:

1. Is the efficacy of the proposed intervention sufficiently well documented to make it a useful clinical treatment?

What is the quality of the existing data from clinical trials or studies on effectiveness and in what populations and settings? There is no point in conducting economic analyses of treatments that are not effective in the first place.

- Are existing clinical trials of efficacy well-designed with robust, valid and relevant outcome measures?
- Having chosen an intervention that is to undergo an economic analysis, one should ask, do the currently available results regarding effectiveness of interventions compare new interventions to existing ones in a practical way – that is, have they been tested in typical settings and patients?
- Can the proposed intervention be delivered in a way which is acceptable to patients so that they will use the health care services offered?
- Will the program of proposed care/intervention be accessible to those who need it (i.e. is it too expensive to buy, too time consuming to use, or too invasive, compared to the current treatments)? There is little point in undertaking economic analysis of a proven effective treatment against a new highly expensive highly specialised treatment that most patients would have trouble accessing, unless it is suspected that the new treatment is markedly more effective. This should be documented by simple outcome studies before going through the extra trouble of performing an economic analysis.

Unless the new intervention and all comparison treatments can give positive responses to the above questions, economic evaluation studies should not be undertaken.

Table 41 Matrix Approach to Economic Evaluation of Continence Conditions
(See below table for Abbreviations key)

CONDITION STAGE	TARGET GROUP	SETTING	INTERVENTION	COST ITEMS	OUTCOMES SUITE	ECONOMIC ANALYSIS
At risk	1. Women after childbirth	Hospital OPD	Physiotherapy training	Personal and treatment costs (DBICI), costs of therapy	None measured	COI
	2. Women after childbirth	Hospital OPD	Physiotherapy training vs. simple education	Personal and treatment costs (DBICI), costs of therapy	Frequency volume chart, pad test, HRQoL	CEA
	3. Women after childbirth	Hospital OPD	Physiotherapy training vs. simple education	Personal and treatment costs (DBICI), costs of therapy	Health preferences, Utility, WTP, QALY, Frequency volume chart, pad test, HRQoL	CUA
	4. Men and Women post-operative	Hospital Wards	Strict catheter management/voiding protocol vs. routine care	IDC, SPC, Flip-flow valve, Ward bladder scanner, expert nurse, DRG based costs	Frequency volume chart, residual volume, HRQoL or QALY not applicable	CEA
Identification of early stage incontinence	5. Men with neurological condition, Alzheimer's, Parkinson's	Community	Early neurological treatment and optimal continence care vs. routine care	Personal and treatment costs (DBICI), costs for neurological treatment and bladder treatment	Frequency volume chart, residual volume, HRQoL, QALY	CEA/CUA
	6. Women postpartum or menopause	Community	Conservative therapy vs. simple leaflet	Personal and treatment costs (DBICI)	Frequency volume chart, pad test, HRQoL	CEA
	7. Women postpartum or menopause	Community	Conservative therapy vs. simple leaflet	Personal and treatment costs (DBICI)	Frequency volume chart, QALY, pad test	CUA
Acute care	8. Patients admitted for surgery to correct incontinence	Hospital	Comparison of different surgical procedures	Direct and indirect costs avoided, DRG based costs	None required	COI
	9. Patients admitted for surgery to correct incontinence	Hospital	Comparison of different surgical procedures	Direct and indirect costs avoided, DRG based costs	Frequency volume chart, pad test, HRQoL	CEA
	10. Patients admitted with another primary condition found to be incontinent	Hospital	See items above Row 4	See items above Row 4	See items above Row 4	See items above Row 4

Table 41 Matrix Approach to Economic Evaluation of Continence Conditions continued

CONDITION STAGE	TARGET GROUP	SETTING	INTERVENTION	COST ITEMS	OUTCOMES SUITE	ECONOMIC ANALYSIS
Acute care continued	11. Ambulatory patients – Men e.g. neurological condition, Alzheimer's, prostatic obstruction	Ambulatory	Early neurological treatment, early prostate treatment	Personal and treatment costs (DBICI), costs for neurological treatment and prostate treatment	Frequency volume chart, residual volume, HRQoL, QALY	CEA/CUA
	12. Ambulatory patients – Women postpartum or menopause	Ambulatory	Conservative therapy vs. simple leaflet	Personal and treatment costs (DBICI)	Frequency volume chart, pad test, HRQoL	CEA
	13. Ambulatory patients – Women postpartum or menopause	Ambulatory	Conservative therapy vs. simple leaflet	Personal and treatment costs (DBICI)	Frequency volume chart, pad test, HRQoL, QALY	CUA
Chronic care	14. Elderly, Frail elderly, Dementia, Neurological disease and spinal injury	Subacute	Timed voiding vs. random toileting	bedside cost records	Frequency volume chart, Nurse administered pad test, HR QoL or QALY by proxy	CEA
	15. Elderly, Frail elderly, Dementia, Neurological disease and spinal injury	Subacute	Disposable continence pad usage vs. linen change	Bedside cost records	Frequency volume chart, Nurse administered pad test, QALY by proxy	CEA
	16. Elderly, Frail elderly, Dementia, Neurological disease and spinal injury	Nursing home	Any of above non-surgical interventions vs. no intervention	Bedside cost records	Frequency volume chart, Nurse administered pad test, no HRQoL or QALY available	CEA
	17. Elderly	Community	Any of above non-surgical interventions vs. no intervention	Personal and treatment costs (DBICI)	Frequency volume chart, pad test, HRQoL	CEA
	18. Elderly	Community	Any of above non-surgical interventions vs. no intervention	Personal and treatment costs (DBICI)	Frequency volume chart, pad test, QALY	CUA

Conservative treatment = Pelvic floor muscle exercises, bladder training, anticholinesterase, oestrogen
COI = Cost of illness analysis
CEA = Cost effectiveness analysis
CUA = Cost utility analysis
DBICI = Dowell Bryant Incontinence Cost Index
HRQoL = Health Related Quality of Life
QALY = Quality-adjusted life year
WTP = Willingness to pay

2. Is there available information on both the costs and the outcomes of the interventions?

- What data on costs and outcomes are required to answer the research question?
- Can these data feasibly be collected?
- Are they very expensive to collect (this was the case for the Sutherland study, refer Section 7)? Do you need specific research staff to collect them or are they routinely collected anyway?

Economic evaluation studies can only be undertaken when information is available on both the costs and the outcomes of interventions. When only cost data are available without any outcome measurement, the only type of analysis that can legitimately be performed is a cost of illness study.

3. Is economic evaluation necessary?

The simplest way to determine whether economic analysis is required is to consider four situations is which costs and outcomes vary.

Table 42 Costs and Outcomes

OUTCOMES	COSTS	
	Increased	**Decreased**
Better	**Required**	Not required
Worse	No need to consider	**Required**

If the outcomes are worse and the costs are higher, there is obviously no need to undertake an economic analysis since the treatment would not be considered at all. If the outcomes are better and the costs are decreased, the treatment would be the preferred option. Economic evaluation is required in two situations: when outcomes are better but the costs are higher, and when the outcomes are worse but costs are lower.

If these latter two conditions exist, the following questions need to be addressed in order to decide whether to go ahead with an economic evaluation:

- Are there large cost implications arising from the intervention under study? For example, if all patients with mild stress incontinence were to be detected and given an operation to cure them, the cost implications would be enormous.
- Do the interventions under comparison differ widely in costs or resource consequences? For example, if all these patients with mild incontinence were given physiotherapy or an operation as part of cost effectiveness analysis, the costs would probably differ markedly and the outcomes may not be greatly different. Such a question has not been answered. This would be worth finding out.

4. What type of economic study is most appropriate?

If outcomes are the same, Cost Minimisation Analysis is the economic study of choice. Most often, there are differences in outcomes, in which case the economic analyses of choice are either CEA or CUA. By definition, most of the research questions that would be clinically interesting would involve a comparison of two different outcomes.

The following table outlines the available economic analyses and gives examples of each.

Table 43 Types of Economic Studies – Examples of Use in Continence Condition

Steps	Cost-of-illness	Cost-minimisation	Cost-effectiveness	Cost-utility
1. Specify question and baseline comparison group	Estimate the costs of managing incontinence in community dwellers; no comparison group	Compare the management of incontinence in the outpatient clinic by a urogynaecologists and a NCA	Observational study of conservative versus surgical treatment for women with moderate stress incontinence	Randomised controlled study of bladder training (BT) versus anticholinergic therapy versus both, for urge incontinence

2. Specify perspective, type and scope of economic evaluation	Societal perspective, cost-of-illness study, costs for one year	Perspective of the hospital and the individual patient, no difference in outcomes between the two providers, therefore cost minimisation analysis	Perspective of the hospital and the individual patient	Health care providers and patients
3. Specify key outcomes and estimation of effectiveness	Not relevant in COI	No key outcomes because previous studies show no difference in outcomes	Frequency Volume Chart, the 24 hour pad test, appropriate HRQoL tests	Frequency Volume Chart, the 24 hour pad test, appropriate HRQoL tests, QALY, Urge-specific quality of life test (the OAB-Q)
4. Define costs to be estimated	Direct costs including continence pads, medical costs, transport (DBICI)	Staff salary costs, tests ordered, treatment costs, time spent with patient	Staff salary costs, tests ordered, treatment costs, time spent with patient, personal costs	Treatment costs and personal costs
5. Estimate quantities in resources used	Nurse administered questionnaire, amounts of consumables and service	Differences in use of services from previous studies	Nurse administered questionnaire, amounts of consumables and service	Nurse administered questionnaire, amounts of consumables and service
6. Estimate unit costs for resources used	Consumable costs, prices for drugs, tests and consultations	Consumable costs, prices for drugs, tests and consultations	Consumable costs, prices for drugs, tests and consultations	Consumable costs, prices for drugs, tests and consultations
7. Specify analytic model	Simple cumulation of costs per patient	Simple comparison of average costs per urogynaecologist and NCA	Simple comparison of difference in costs with difference in outcome measures	Simple comparison of difference in costs with difference in QALY
8. Consider time preference	Not applicable in short time frame	Short term follow-up, no long-term costs to discount	Short-term for follow-up, so not relevant	Future health gains and costs discounted
Steps	**Cost-of-illness**	**Cost-minimisation**	**Cost-effectiveness**	**Cost-utility**
9. Summarise economic results	Cost per incontinent community dwelling patient	Difference between average cost per visit per urogynaecologist and NCA	Incremental cost per quality of life and health indices	Incremental cost per QALY
10. Do sensitivity analysis	Vary unit costs and usage	Vary unit costs and usage	Vary costs of alternative treatment options	Vary costs of alternative treatments

Adapted from Jefferson et al. (1996)

16.4 Point Scoring System for Evaluation of Proposed

Economic Analyses

As a result of conducting the literature review and pilot substudies, the Project Team has acquired an overall perspective as to how best to carry out future economic analyses. The scoring system was applied by A/Prof K. Moore and Dr Tessa Ho independently, reconciled, and the results were presented to Dr Helen Lapsley for final comment.

For example, at the start of this Project, the concept of Burden of Disease was largely unknown to some team members, and its importance in the overall development of an economic framework about incontinence was not fully appreciated. The team now believes that the value of future projects should be partly judged on the basis of whether the type of incontinence to be studied carries a major Burden of Disease.

A concept that is of secondary but parallel importance is the prevalence of the condition. The team would place a low priority upon funding a study regarding an incontinence type that is very rare (unless it carried an exceedingly large burden of disease).

Whilst these two concepts are theoretically very important (and hence are first in the list given below), in practical terms it is not possible to conduct an economic analysis unless adequate outcome measures are available for the condition to be studied. Hence this criterion receives one of the highest point scores. Secondly, the team believes strongly that funding should not be supplied for a project which is not original. If similar work has been carried out overseas, it should not be repeated in this country unless the conclusions are rendered inapplicable to Australian health care or the Australian economic environment by fundamental differences in conditions of the study. Such differences do occur when comparing some American studies to Australia.

The Team believes that Outcome Measures and Originality are absolute high priorities, whereas Burden of Disease or Prevalence may vary in the priority scale according to value judgements made by the funding body. For example, some conditions that are not highly prevalent may still be of great interest to a particular funding body.

The lesser point scores were then assigned to issues such as Economic Rationale, Overhead Costs, Data, and Expense of Study. These issues are of lower intellectual priority but are necessary for the ranking of studies in practical terms.

5. What study will give the most value to the health care system – a point scoring system:

Each category below can receive a maximum score shown in the brackets, total score for all seven = 100.

I. The first criterion should be – does the study concern a type of incontinence that contributes a large burden of disease? For discussion of this see Section 5 and Appendix B. For example, patients with neurological incontinence (as described by the case studies in Appendix B) have life long severe leakage that is expensive to contain. Also, patients described in Caroline Dowell's pilot of home dwelling elderly, have severe debilitating incontinence that renders them social recluses. **[Burden of Disease: 15]**

II. The second criterion should be – is the condition highly prevalent? In other words, what percentage of the population does it affect? **[Prevalence: 15]**

III. The third criterion should be – are there good quality/robust outcome measures to show the value of the comparative treatments. For example, there are few specific outcome measures for patients with dementia who are incontinent (they cannot fill in a frequency volume chart, nor complete a quality of life test, they are usually too frail to undertake a 1 hour pad test, and they can only undertake a 24 hour home pad test if they have a constant carer). Hence although dementia-related incontinence is associated with a large burden of disease and is fairly prevalent it is difficult to perform economic analysis of incontinence treatments in this area, as few outcome measures are suitable. Project one recommended the FIM Score, which must be done prospectively with great care, or the Barthel Index, which also needs trained staff. **[Outcomes: 20]**

IV. The fourth criteria should be – is this data/proposed economic evaluation available from overseas work, and if so, is it necessary to conduct it in the Australian environment in order to inform Australian health care providers. For example, since the literature review was undertaken, a cost utility analysis of colposuspension operation versus Tension Free Vaginal Tape procedure has

been undertaken in Britain. This certainly would not require repeating in Australia, as the overall funding environment is sufficiently similar to allow appropriate conclusions to be applied to Australia. **[Originality: 20]**

V. The fifth criterion should be – what is the economic rationale or justification for performing the study. For example, operating on all patients with mild stress incontinence would not be a sensible economic study (because 65 per cent of these patients can be cured by conservative treatments). However, operating on all patients with severe stress incontinence (in an RCT of two operations) would be a useful economic question, since it is not generally believed that many such patients will be cured by physiotherapy. **[Rationale: 10]**

VI. The sixth criteria should be – what is the quality of data available about overhead costs in the particular care setting. In the pilot studies conducted, overhead costs were rarely available. Before funding a large economic analysis, the availability of overhead cost data (or accurate estimates) should be checked. **[Overhead Cost Data: 10]**

VII. The final criteria should be – what is the cost of collecting the economic data? For example, in the pilot study of nurse continence advisors (NCAs) in the acute hospital, the NCA was shadowed for three days to provide time and cost data for each clinical activity, which could be reliably extrapolated across a large sample size. On the other hand, the Sutherland Hospital Sub Acute Care study required detailed bedside costing by staff with an appropriate research infrastructure. It will be important to balance the cost of collecting the data with the usefulness and ability of that data to be generalised. **[Expense of Study: 10** – higher score = cheaper study]

16.5 Suggestions for future studies of the effectiveness and economic analysis of continence treatment

Following the discussions between the project teams (held on 18 July 2002 and 20 August 2003 and at a workshop held in December 2003 at the CFA conference) the following concepts have been further developed:

The teams explored the concept that to fill one of the major gaps identified, a study of women aged 40-65 years attending an Outpatient Unit over 2 years would be conducted, to examine the cost effectiveness and health related quality of life (HRQoL) benefit of conservative therapy. It is now felt that this should be split into two separate studies, relating to the two main diagnoses of detrusor overactivity (urge incontinence) and urodynamics stress incontinence.

1. A randomized controlled study of bladder training (BT) versus anticholinergic therapy versus both, for urge incontinence.

As discussed by the Project Team, the Cochrane Incontinence Group is currently undertaking a pilot randomised controlled trial of this research question, to enable accurate power calculation yielding a rational sample size. The Cochrane group (based in Dunedin) will then seek funding for a multi-centre trial. We suggest that NCMS funding be devoted to this project, as it is one of the most important and poorly understood issues in the field of continence management. A subset analysis of the elderly (age >75 years) could be included within this project, which would address the issue of managing continence in the home dwelling elderly before they become so severely affected that nursing home admission is contemplated (usually associated with co-morbidities such as immobility, poor mental capacity, and recurrent falls).

The Cochrane Incontinence Group would be willing to adopt the Outcome Measures recommended by Project 1 and the Economic Analysis recommended by Project 2. Specifically, these would be the Frequency Volume Chart, the 24 hour pad test, appropriate QoL tests and a health utility index, along with measuring the costs of treatment and the personal costs. The Cochrane Incontinence Group has also nominated an urge-specific quality of life test (the OAB-Q) that will be included (Coyne et al. 2002).

Score: **Burden 14/15, Prevalence 14/15, Outcomes 19/20, Originality 19/20 Rationale 9/10, Overheads 5/10, and Expenses 8/10** ***Total:*** **88/100**

2. Markov Model for the Management of Incontinence in Australia: As regards a Markov Model for incontinence, Ramsay undertook such a hypothetical analysis of the total costs of urinary incontinence treatments in the US, using a decision tree as dictated by the US AHCPR clinical practice guidelines in 1996. However many aspects of these AHCPR guidelines are now out of date, i.e. the management practices have changed since 1996. Nevertheless, the authors of the current Project are of the opinion that

funding a study of incontinence treatment costs using a Markov Model based on current management guidelines (WHO) would be very informative. New data about current management practices would be required to undertake this, however (see 2.3.3.4).

> ***Score:*** **Burden 7/15, Prevalence 15/5, Outcomes 18/20, Originality 19/20 Rationale 10/10, Overheads 8/10, and Expense 8/10** ***Total:*** **85/100**

3. Treatment/Prevention of Incontinence in Post partum women: Although Chiarelli has demonstrated high uptake of postpartum incontinence treatment and others have demonstrated efficacy of this regime (Morkved et al. 2003), no study to date has undertaken any economic analysis. Morkved et al. estimated that 6 antenatal women would need to be treated to prevent one case of postnatal incontinence. The costs of a conservative treatment programme by a physiotherapist, versus usual care (leaflets in the postnatal ward), has not been assessed. A risk scoring system could be developed to increase the yield of the treatment, e.g. rather than treating all postnatal women, those who are obese and constipated could be considered. The study would require a long duration of follow up because spontaneous cure of postnatal leakage is known to occur. A Markov type analysis of this particular problem would also be useful.

> ***Score:*** **Burden 9/15, Prevalence 13/15, Outcomes 19/20, Originality 16/20 Rationale 7/10, Overheads 5/10, and Expenses 8/10** ***Total:*** **77/100**

4. Study of Incontinence treatment in the General Practice setting: One further trial that would appear very useful is that of incontinence treatment in the General Practice setting. This would require collaboration with a Division of General Practice. An RCT of intensive therapy from dedicated nurse continence advisers, physiotherapist, urologist and urogynaecologist, for half of the study participants versus simple verbal instruction in the remainder, could be undertaken. Subset analysis would allow identification of the elderly home-dwelling patient with incontinence. This study should exclude severe incontinence (because the cure rate for conservative therapy in severe cases is less than 35 per cent) and focus on mild-moderate leakage. Data collection would be expensive in order to ensure GP collaboration, and the study would be generally difficult to conduct in our experience.

> ***Score:*** **Burden 13/15, Prevalence 12/15, Outcomes 19/20, Originality 18/20 Rationale 8/10, Overheads 5/10, and Expense 1/10** ***Total:*** **76/100**

5. A pragmatic study of conservative versus surgical treatment for moderate stress incontinence. Because mild stress incontinence has a 50-65 per cent cure rate resulting from conservative therapy, systematic study of this mild group is not a high priority. Similarly, severe incontinence (24 pad test >75ml) has an 88-95 per cent cure rate from surgical therapy. The unknown question is the best way to manage moderate incontinence, because the cure rate for conservative therapy in this group is only 35 per cent over 3 years (Moore et al. 2003).

An observational study of women with moderate incontinence is proposed. Patients with moderate stress incontinence would be allowed to choose conservative therapy (of whom 35 per cent will be cured). The 65 per cent who choose conservative therapy but fail to achieve cure then may choose surgery, a second arm of the study. Thirdly, some patients may choose surgery as first line therapy (of whom 85-93 per cent will achieve cure). It would be unethical to randomise patients, but a pragmatic trial would have greater meaning for the practicing clinician. Appropriate outcome measures and economic analyses would be incorporated.

The QoL benefits for each of these 3 strategies are unknown, and the costs are unknown. For example, patients with moderate incontinence may feel more satisfied if they have worked through the process of conservative therapy but failed and moved onto surgery, compared to those who opt for surgery, of whom a proportion will encounter complications such as incomplete emptying (5 per cent) recurrent UTI (2 per cent) or de novo urgency and urge incontinence (10-15 per cent). The costs of conservative therapy are substantial (e.g. weekly visits x 12 weeks) but the costs of surgical complication are also high. We do not know whether the overall balance (with benefits measured in Quality of Life years) would favour a conservative or surgical approach in moderate incontinence. Considering that many elderly women (age >75 years) now opt for minimally invasive surgical techniques (tension free tape procedure under local anaesthesia), stratified analysis of the elderly costs and outcomes would be very informative as this has not been investigated in any of the literature to date. Such a study would yield important data that could allow a Markov Model to be completed.

> ***Score:*** **Burden 9/15, Prevalence 10/15, Outcomes 19/20, Originality 17/20 Rationale 8/10, Overheads 5/10, and Expense 5/10** ***Total:*** **71/100**

6. Study of frail elderly living at home, analysing use of private nursing services: Our recent enquiries into home nursing services reveal that almost 90 per cent of users are subsidised by DVA or other subsidy schemes, very few such services are paid for privately. Such a study would reveal much about the intangible costs of suffering, since many of these patients become social recluses owing to their incontinence. One research question could be suitable for economic analysis in this environment. A subset of these elderly patients, who have a main complaint of stress incontinence, could undergo treatment with the Bladder Neck Support Prosthesis (BNSP), compared to simple pelvic floor exercises as part of an RCT. It is known that the BNSP achieves continence in 86 per cent of women who can be fitted, and it is suitable for use in the frail elderly. Outcomes may still be difficult in this frail elderly group, Project 1 (Outcomes Measurement Suite) recommends FIM Score and Barthel Index, but a carer-completed form could be used (although not yet validated).

> ***Score:*** **Burden 15/15, Prevalence 8/15, Outcomes 13/20, Originality 16/20 Rationale 6/10, Overheads 5/10, and Expense 8/10** ***Total:*** **70/100**

7. Study of Costs of managing intractable chronic urinary incontinence in the Community-dwelling neurological patient: Throughout the conduct of this Project, and especially during discussions of Burden of Disease, it became apparent that the Project has not captured the costs of neurological incontinence in patients who live at home. Neurological incontinence was studied only in hospital inpatients. The case histories from the CFA document are the only aspect of this report which touches on these patients. Such a study would be made difficult by the fact that many neurological patients cannot complete Quality of Life questionnaires, but their carers could fill them in by proxy. Such a study would address gaps in our knowledge of Burden of Disease.

> ***Score:*** **Burden 15/15, Prevalence 8/15, Outcomes 10/20, Originality 20/20 Rationale 5/10, Overheads 5/10, and Expense 5/10** ***Total:*** **68/100**

8. *Faecal Incontinence in Pregnancy:* As regards faecal incontinence in pregnancy and the postpartum period, a few studies have considered the benefits of early detection and primary care management in the puerperium, but none of these studies provided any cost data whatsoever (and thus have not been included in the literature review). However, we believe that a study of such interventions that included costs of early treatment versus costs of usual management (simple leaflets given out in postnatal wards) would be extremely useful. Such data could provide information about the cost per case of faecal incontinence prevented. A randomised controlled trial or a pragmatic management comparison in two separate units would both be informative.

> ***Score:*** **Burden 5/15, Prevalence 5/15, Outcomes 15/20, Originality 18/20 Rationale 9/10, Overheads 5/10, and Expense 8/10** ***Total:*** **65/100**

9. Study of the treatment of urinary retention and overflow: This study still has considerable appeal, but would require help from an urologist. Patients who are admitted to hospital either with prostatic hyperplasia or with other conditions, who are found to be in acute urinary retention, require catheterisation and then repeated "trial of void" episodes before their catheter can be completely removed. A great deal of nursing time and hospital days is spent on these patients. Formal economic analysis would be difficult as it is difficult to envisage a "control" arm hence it would be a Cost of Illness Study.

> ***Score:*** **Burden 6/15, Prevalence 5/15, Outcomes 10/20, Originality 13/20 Rationale 2/10, Overheads 4/10, and Expense 6/10** ***Total:*** **46/100**

10. Audit study examining acutely admitted elderly incontinent patients: To track those who remain in inpatient beds while seeking a nursing home placement. This project is also not a high priority, as it is a purely observational study, allowing little chance for formal economic analysis (little opportunity for a "control" group). No outcomes are available for such a study. It would have far reaching cost implications however.

> ***Score:*** **Burden 10/15, Prevalence 3/15, Outcomes 0/20, Originality 15/20 Rationale 5/10, Overheads 3/10, and Expense 8/10** ***Total:*** **44/100**

Conclusions:

In summary, the authors have identified the most appropriate methods for conducting cost studies and economic analysis to fill the gaps in our knowledge of Australian Continence Care. The broad overview of available studies contained in the matrix has been further developed to produce a series of desirable economic analyses. These have then been scored according to seven economic and clinical criteria to identify the highest "priority" or "value for money" studies. The first 3 are considered to be urgent priorities and the remaining 7 are also of considerable value, depending upon the funding available.

This scoring system has identified the most original, robust, practical and important studies from the Team's perspective. However some of the projects have received lower scores based on the Project Team's judgement. For example, the study of urinary retention was given a low score partly because it is not highly prevalent. However, a funding body may decide that this particular issue is a high priority. All scoring systems involve some value judgements.

From the Pilot Studies it is evident that the research requirement of future studies should not be underestimated, as it was found virtually impossible to incorporate vigorous data collection into frontline clinical work.

The research identified here requires appropriate funding so that health resources relating to incontinence in Australia can be identified with regard to both equity and efficacy consideration, and so that future resource needs can be estimated.

Appendix B – Excepts from Continence Foundation of Australia Position Paper – Literature Reviewed*

Article	Country	Incontinence Type	Client Group	Treatment Intervention	Care Setting	Study Type	Outcome	Study Value	Comment
Anand (1990)	US	Urinary general	Elderly	Nil specific	Nursing home	Review	CA	Low	Review article on aging. Value lies in its mention of Ouslander (1984) to support global and projected costs – no new material – limited value.
Beckman (1995)	US	Urinary general	General	Nursing	General	Review	CA	Low	Review article with a focus on nursing intervention. Value lies in its mention of AHCPR (1992) and projected savings from following guidelines.
Berman (1996)	US	Urinary – Stress	Women	Surgical	Acute	Cost comparison	Yes	Medium	Provides evidence to indicate that although Collagen is less costly than a Sling the outcomes may not be as good as reported in other studies. However, different follow-up times between the two groups weaken this study (n = 28) Costs based on US hospital charging data.
Borrie (1992)	Canada	General Urinary and/or Faecal	Nursing Home Patients	CA	Long Term Care	Cost of care	No	Medium	Proves evidence that mobility and mental function account for 44 per cent of variance in urinary incontinence. Costing while not sophisticated provides a useful basis for costing incontinence care in nursing home environments. Refers to Cella (1988)
Brown (1998)	US	Urinary	Men – post prostatectomy	Surgical and Non-Surgical	Acute and community	Cost comparison	No	Low	Uses Mayo Clinic charging data for Collagen, AGUS and Pad management. Provides a useful review of studies in this area. Weak methodology for estimating 10 year costs of care. Reveals that AGUS is less costly where >3 Collagens are required or patient wears >9 pads per day for 10 years. Does not seek to value psychosocial benefit of continence.

Article	Country	Incontinence Type	Client Group	Treatment Intervention	Care Setting	Study Type	Outcome	Study Value	Comment
Clayton (1998)	UK	Urinary	Women including disabled	All services	All settings	Cost of illness	CA	High	Part of a larger NHS study to integrate consumer views into policy and purchasing. Worth following up overall approach and further reports. Cost data was collected from clients and local and national datasets. A Service Receipt Schedule was developed to survey costs from Beecham (1995).
Coleman (1999)	US	Urinary	Frail elderly	Primary care clinic.	Community	Cost comparison	Yes	Medium	Compares outcomes of usual care with an implementation of new primary care model for the frail elderly. Incontinence was one of the key measures. Small sample size, limited study power and no significant differences were detected. Randomisation occurred at the level of the practice not doctor or patient.
Cummings (1995)	Canada	Urinary	Frail elderly	Non invasive – toileting, fluid intake, drugs etc.	Nursing home type setting.	Cost comparison	Yes	Medium	Changes to incontinence management produced 13 per cent reduction in incontinence episodes and increase in HRQoL. Costing indicated no change in overall care costs. Useful – indicates there may be best practice in incontinence management in Nursing Homes.
Curtis (1997)	US	Urinary	Women	Surgical	Acute	Cost comparison	No	Low	HMO billing data for a sling procedure was analysed to assess changes in charges from a cost review of the procedure. Reduced LOS (self catheterisation education) accounted for the majority of cost reduction. Sample n = 15 in intervention group. Not very useful.

Article	Country	Incontinence Type	Client Group	Treatment Intervention	Care Setting	Study Type	Outcome	Study Value	Comment
Dolman (1988)	UK	Urinary	Elderly	Pads	Nursing home	Cost comparison	No	Low	Compare cost of disposable and reusable pads. Very little value.
Doran (2001)	Australia	Urinary	Women	All services	Community	Cost of illness	CA	High	Australian cost of illness study. Utilises Dowell Bryant Incontinence Cost Index on n = 100 community dwelling women (Dowell, 1999). Admitted care costs appear to only reflect professional service costs and thereby underestimate overall costs. Methodologically less sophisticated than Hu (1986).
Dowell (1999)	Australia	Urinary	Women	All services	Community	Cost of illness	CA	High	Costing relies on client survey and recall. Hospital based costs understated as only professional services were costed. Casemix prices would enhance this costing. Only direct cost numerated. Provides reasonable basis but should be evaluated alongside other such measures (eg. UK).
Eriksen (1989)	Norway	Urinary – Stress	Women	Electrostimulation	Community	Cost comparison	Yes	Low	Estimated cost of leave, social expenses and hospitalisation for surgery was compared with cost of stimulation. Successful outcomes from stimulation reduce need for surgery – weak methodology but study provided evidence that stimulation was cost-effective, n = 55.
Forneret (1985)	US	Urinary – Stress	Women	Surgical	Acute	Cost comparison	No	Low	Rather weak study that showed that LOS for two procedures differed and hence charges. Largely due to pre-operative training to self catheterise. Little value to study, n = 82.

Article	Country	Incontinence Type	Client Group	Treatment Intervention	Care Setting	Study Type	Outcome	Study Value	Comment
Gomes (2000)	US	Urinary	Men – post prostatectomy	Surgical	Acute	Cost comparison	Yes	Low	Retrospective study of 30 men who underwent artificial sphincter surgery. Found those men who had collagen first raised direct cost by 86 per cent – did not affect surgical outcomes – indicates some cases would benefit from surgery without collagen. Study does not assess the extent to which collagen reduces need for sphincter surgery. Not particularly useful. Similar to Brown (1998).
Hollywood (1998)	UK	Urinary	Women	CA	General Practice	Review	CA	Low	Commentary on management by GPs. Refers to two articles in same issue that evaluate general practice. Follow-up of articles could be useful.
Hu (2000)	US	Urinary – overactive bladder	General	CA	General	Review	CA	Medium	An overview article looking at calculating the economic burden of incontinence on society and economic evaluation of specific interventions with specific mention of difficulties with intangible costs. No new information. Relative little value to study.
Hu (1990)	US	Urinary	General	CA	Community and Nursing Home	Review	CA	Medium	Useful review article that sets out many of the issues with costing the impact of incontinence on society including the lack of reporting on incontinence related service utilisation. A key aspect that could be taken up our work.
Hu (1986)	US	Urinary	Elderly	CA	Community and Nursing Home	Cost of illness	CA	High	Clearly a seminal piece of work that draws on various studies and extrapolates to US epidemiological data. Valuable article from which to develop a top down approach to quantifying the cost of incontinence in Australia, should that be desirable. Doran and Dowell are examples of work in Australia.

Article	Country	Incontinence Type	Client Group	Treatment Intervention	Care Setting	Study Type	Outcome	Study Value	Comment
Johannesson (1997)	Sweden	Urinary – Urge	General	CA	CA	Willingness to pay	No	High	Willingness to pay for a reduction in frequency of micturitions and leakages was assessed. This is one way to estimate the cost of incontinence for individuals, including indirect and intangible costs. Does not measure externalities/vicarious benefits. Lack of demonstrated correspondence between hypothetical questions and real behaviour reduces validity of this technique. Useful for input into the study but action reliance.
Kobelt (1997)	UK	Urinary – Urge	General	CA	CA	Review	CA	High	Largely a review article that takes up the need for outcome measures – willingness to pay (Johannesson) is discussed along with QALYs etc. and discusses cost of disease approaches including Hu. Includes useful comment from Drummond and Resnick.
Korn (1996)	US	Urinary – Stress	General	Surgical	Acute	Cost of care	No	High	Using ICD 9 codes the rate of operations for stress incontinence were identified in the US. Interesting that actuals are greater than Hu estimates even though coding deficiencies obscure true incidence of relevant operations. This article provides a basis for an Australian study using the National Hospital data collection and would enhance data from the Dowell Bryant Index.

Article	Country	Incontinence Type	Client Group	Treatment Intervention	Care Setting	Study Type	Outcome	Study Value	Comment
Kornides (1999)	Australia	Urinary	CA	CA	CA	Review	CA	Low	Short paper that presents market based data on pad sales in 12 countries and plats alongside GDP and population. Indications that public financing, wealth, culture and prevalence may be active in usage.
Kung (1996)	Canada	Urinary – Stress	Women – general	Surgical	Acute	Cost comparison	Yes	High	Relatively detailed cost-effectiveness study, including sensitivity analysis. Uses billing data and hospital costing data to assess costs. Only direct and indirect hospital costs measured. Results could be biased by age and follow up differences between groups. One of the more rigorous/documented studies.
Lan (1992)	Denmark	Urinary – all	Women 35-49	CA	CA	No costing	No	Medium	Interesting survey study that indicates that while incontinence may not be a socially disabling condition for women 35-49 it consequences for everyday life are widespread. Differences between stress and urge incontinence are explored. Provides useful material although somewhat dated.
McCormick (1990)	US	Mainly urinary	Female	Prompted toileting	Nursing home	Cost comparison	Yes	Low	Only 10 clients in the study. However, interesting analysis of costs of consequences of immobility and incontinence by looking at the change in wetness, UTI and ulcers from prompted toileting using a lifter. Costing does not have external validity and subject to scale variation.

Article	Country	Incontinence Type	Client Group	Treatment Intervention	Care Setting	Study Type	Outcome	Study Value	Comment
McGhan (2001)	US	Urinary – urge -OAB	General	Mainly pharmaceutical	General	Review	CA	High	Useful recent review article that sets out many of the HRQoL and cost aspects of urge incontinence. Although focus on pharmaceutical applications, reference list is quite broad and extensive.
McGhee (1997)	UK	Urinary – all	General	Varied but conservative	Community and Nursing Home	Cost comparison	Yes	Low	Interest of this article lays with its focus on the impact of community nurse care plans for community, nursing home and long term care hospital patients. Different strategies were used in each setting, but all showed improved outcomes. Poorly documented study with a flawed costing methodology.
McClish (1999)	US	Urinary – stress	Women 45+	CA	Community	Cost of care	No	Medium	Pad use diary of 315 community dwelling women from 3 cities. Cost of pad usage was significantly associated with quality of life and number of incontinent episodes but not age or duration of incontinence. Value for study – compare with other pad usage studies in Australia.
McMurdo (1992)	UK	Urinary – general	Elderly	Catheter v pads	Long term care hospital	Cost comparison	Yes	Medium	Study looking at comparative costs of caring for clients with incontinence using catheter or pads and toileting. Strength of study lies in randomisation. However, problems with consent and subsequent changes in management illustrate difficulties with such, particularly with frail elderly population.
Mattiasson		Urinary – general	CA	CA	CA	No costing	CA	Low	Limited use to study. Recommends development of incontinence specific outcomes measures (e.g. controlled days).

Article	Country	Incontinence Type	Client Group	Treatment Intervention	Care Setting	Study Type	Outcome	Study Value	Comment
Mellstrom (1988)	Sweden	Urinary – general	Elderly women	Varied.	Hospital mainly	No costing	CA	Low	Older study – no costing. Initial report on a comprehensive medical management protocol for elderly incontinent women in Sweden. No value to this work.
Midgard (1996)	Norway	Urinary – general	MS patients	CA	Hospital	No costing	CA	Low	Only value lies in the fact 15 per cent of an incident sample of MS patients in Sweden had frequent incontinence.
Milsom (1993)	Sweden	Urinary – general	Women 46 – 86	CA	CA	No costing	CA	Low	No costing. Prevalence study that demonstrated age and parity correlations. Limited value to study.
Moore (1999)	Australia	Urinary – all	Women	Urethral occlusion device	Community	No costing	CA	Low	Of limited use to study. No costing. Limited timeframe for outcomes could reduce validity of results.
Moore (2001)	Australia	Urinary – general	General	CA	CA	Review	CA	Medium	Context setting article that identifies the dearth of costing studies in Australia.
Netto (1988)	Brazil	Urinary – stress	Women 32-65	Stamey/modified	Acute	No costing	CA	Low	Of little value to study. Comparative study of two techniques. Results indicate the modified technique was not as effective.
Nordqvist (1984)	Sweden	Urinary – general	Male and female with indwelling catheters.	Catheter v conservative management supported by drugs	Long term hospital care	Cost comparison	Yes	Low	Old study with poor costing methodology and questionable comparison between control and study groups. Looked at costs and outcomes of long term aged care clients – catheterisation v conservative management. Limited value.

Article	Country	Incontinence Type	Client Group	Treatment Intervention	Care Setting	Study Type	Outcome	Study Value	Comment
O'Conor (1998)	US	Urinary – urge and mixed	Not specified.	CA	CA	Willingness to pay	CA	Medium	This study records the SF 36 scores of 411 clients with urge or mixed incontinence and compares with US general population. Plus using a contingent valuation survey sought to measure willingness to pay. Link with Johannesson. Useful in willingness to pay section.
Ouslander (1984)	US	Urinary – general	Frail elderly	Various	Nursing home	Cost of care	No	High	Seminal study along with Ouslander (1982). Old now but detailed costing method that looked direct costs of incontinence and costs of the consequences (e.g. UTI). Worth looking up citations of this paper to see more recent studies in this area.
Ramsey (1996)	US	Urinary – stress	Elderly women	Various	Community	Cost comparison	Yes	High	Interesting study methodology using a decision tree approach and Markov cohort simulation. Taking the AHCPR clinical practice guidelines for incontinence the researchers seek to compare the costs of behavioural, drug and surgical intervention with a "no treatment" over a 10 year period. While results vary for 1 year and 10 year outcomes, overall intervention is less costly than intervention with surgery less costly in the longer run. This model provides an interesting alternative to Hu and reminds me of Diabetes in its cohort approach.

Article	Country	Incontinence Type	Client Group	Treatment Intervention	Care Setting	Study Type	Outcome	Study Value	Comment
Sampselle (2000)	US	Urinary – general	Women	Primary care protocol	Community nursing	Cost comparison	Yes	Medium	Women in an ambulatory women's health care setting. Nursing protocol for screening, and bladder and pelvic floor exercises. Displayed improved outcomes and reduced self care costs. Important study although outcomes were not astounding.
Schnelle (1995)	US	Urinary – general	Elderly – dementia	Prompted voiding	Nursing home	Willingness to pay	CA	Medium	This study did not focus on client outcomes but on the cost of promoted voiding and family preferences using a quasi form of willingness to pay. Study technique was required given HRQoL challenges with demented clients. Reduced cost of "consequences" of incontinence not evaluated.
Scnelle (1988)	US	Urinary – general	Frail Elderly	Prompted voiding	Nursing home		Yes	Medium	Reasonably strong costing methodology showed that while a prompted voiding strategy reduced incontinence in nursing home residents it added to the cost of care. Without evidence of increased HRQoL or reduced consequences (UTI), the change in cost is hard to justify from an economic perspective
Simons (2000)	Australia	Urinary – all	Women	Urethral occlusion device	Community	Cost comparison	Yes	Medium	Study reveals that personal direct costs as measured by Dowell Bryant Index are correlated to other outcome measures. The corollary being that incontinence has direct impact on personal costs. Linked to Moore (1999)

Article	Country	Incontinence Type	Client Group	Treatment Intervention	Care Setting	Study Type	Outcome	Study Value	Comment
Sowell (1987)	US	Urinary – general	Frail Elderly	Pads and toileting	Nursing home	Cost comparison	No	Medium	Extensive costing of 4 absorption products and toileting. Variability in efficiency of products and staff costs. Toileting most labour intensive. However author argues that no additional staff cost would be incurred within usual staff levels – motivation is the key.
Thom (1998)	US	Urinary – all	Various	CA	Community	No costing	CA	Medium	Study explores factors for variable prevalence reporting from population based surveys. Frequency of incontinence, age and gender explains much of the difference. Definition and nature of survey questions were not explored but potential causes of variance too.
Thomas (1980)	UK	Urinary – all	Various	CA	Community	No costing	CA	Low	One of the studies reviewed by Thom. 18,000 respondents to survey. Would be interesting to compare Australian figures in Doran but of low value to this work.
Versi		Urinary – general	CA	CA	CA	Review	CA	High	Good review article that covers many points of relevance to the study in a general sense.
Wagner (1998)	US	Urinary – general	65+	CA	CA	Cost of illness	CA	High	This study updates Hu (1996) from 1984 to 1993 dollars. A significant update is in respect to treatment – now split between surgery, pharmacology and behavioural. This is probably the benchmark study for cost of illness. But note it covers only the 65+ cohort.
Wagner (1996)	US	Urinary – general	CA	CA	CA	No costing	CA	Low	HRQoL measure. Little relevance to costing focus of this work.

Article	Country	Incontinence Type	Client Group	Treatment Intervention	Care Setting	Study Type	Outcome	Study Value	Comment
Watson (1990)	UK	Urinary	Not specified	Sheath v absorbent products	Not specified	Cost comparison	No	Low	Active research of ward cost experience with different incontinence products. Little detail of methodology. Rather weak study with little value for this work.
Weber (2000)	US	Urinary – stress	Women with pelvic organ prolapse	Office evaluation v urodynamics testing	Preoperative	Cost comparison	Yes	Medium	Compares office evaluation and urodynamics testing for accuracy in assignment of diagnosis by means of decision-analytic approach. Costs were derived from DRG data and other relative value units for other professional services. Interesting and relatively sophisticated methodology but of limited value to this work.
White (1993)	UK	Urinary	Spina bifida	CA	CA	Cost of care	No	Low	A rather informal account of one client with spina bifida. A costing of his incontinence is given but given the nature of the costing it has no external validity.
Wielink (1997)	Netherlands	Urinary	Spinal injury	sacral rhizotomies and electrical bladder stimulation	Acute	Cost comparison	Yes	High	Good study that provides a strong cost analysis. Demonstrates that while initial costs of rhizotomies are high the resultant savings in self care and drugs suggest that the total cost of conventional care is higher after about 8 years.
Zorn (1999)	US	Urinary – idiopathic urge.	General	CA	CA	No costing	CA	Low	No costing data. Study explores correlation between depression and incontinence due to altered serotonin function.

* CA = Cost of Care Analysis, as defined in Section 2.3.2

towards an Equitable National Scheme for Continence Products

Case Study 1: "Sorry, it's not a happy birthday!" CAAS cut off at 65 years of age

D is a 66-year-old woman with bladder and bowel incontinence due to paraplegia, which she sustained after an accident 40 years ago. D lives with her husband and they have an Aged Pension.

D has been using intermittent self-catheterisation since 1993, and obtained her equipment for bowel and bladder management through CAAS. She turned 66 on the 7th January 2000 and ceased to be eligible for CAAS despite the fact that she still continues to do voluntary work and her condition is not expected to alter, nor has the type of supplies she requires changed.

D applied to ACTES (PADP scheme in Australian Capital Territory), but they only supply 90 catheters per 3 months, for which D pays $20.00. All her other equipment such as pads, aperients, antibacterial solutions, are now purchased at the chemist or supermarket. **This cost is estimated to be near $1,000 per year, which she must find from her pension.**

Case Study 2: "Sorry, you are ineligible" – Continuing to work at 64 years so she can afford to maintain social continence

H is a 64-year-old woman with multiple sclerosis and resultant bladder and bowel incontinence. H still works 20 hours per week. She manages her bladder incontinence with clean intermittent self-catheterisation four times per day. All catheters are single use items, thus costly. She manages her bowel incontinence with extensive medication and bed protection. H has to take additional precautions to reduce infections, thus has additional costs for antiseptics medicated wipes etc.

H does not qualify for any subsidy scheme. **Her costs are estimated at $3,000 per year, which represents 15 per cent of her income** and consequently greatly limits her lifestyle choices.

Many children do not qualify for a subsidy scheme. Their families supply all their own products, provoking considerable financial hardship. For example, see case study 3 below.

Case Study 3: "Sorry, you are too young!" – A 4-year-old with a congenital abnormality doesn't fit the eligibility criteria

J is a 4 year old girl born with an abnormality of her urogenital tract and anus called cloaca for which she has had multiple operations. J and her older brother are cared for by their parents. J's father works part time (at night) so he can provide J's full time care during the day, because J's mother is the main financial provider for the family. The family receives a Carer's Allowance of $76.40 per fortnight. J cannot stay in childcare, because a stay longer than 2- 3 hours would require community nursing support.

J has had recurrent urinary tract infections that require hospitalisation. During these times a parent stays with J, and therefore time has to be taken off work to care for her brother at home. J's incontinence limits family holidays and outings to public changing facilities with a large change table that is clean enough to allow for hygienic intermittent catheterisation.

J has a urinary stoma to allow for bladder catheterisation 4 –5 times per day. She uses intermittent urinary catheters obtained via a stomal association. She also uses taper tip catheters at times due to stomal stricture: these cost $3.80 each (average $7/month). Overnight drainage bags are used p.r.n., at approximately $7.00 per month.

J's faecal incontinence is managed with 6-10 nappy changes per day. J takes an oral stool softener daily to prevent constipation. Nappies cost approximately $90 per month. These are purchased from supermarkets and chemists. The family purchase especially designed disposable "swim pants" for swimming. The cost of medication such as laxative and antibiotic therapy is approximately $7.00 per month. Each private visit to a health professional relating to continence needs incurs a gap fee. **The cost to this family is in excess of $1,500 per year. They are not eligible to receive any subsidy.**

Feedback from professionals provides examples of clients who have returned to work (after battling cancer) so they can afford to purchase the incontinence products they need. Others have been on waiting lists for services for three years and have sold household articles to pay for incontinence products.

Some have traded in child's respite hours to purchase incontinence products. Cases exist in which families have been soliciting extra funds from charities "cap in hand", just to purchase incontinence products. Clients may have re-useable products available to them on subsidy schemes, but then cannot launder them due to their physical disability. Desperate measures such as using extended disposable nappies with tape to enable cheaper sizes to be purchased are also recorded.

Such anecdotes are indicative of the absolute indignity created by the increased financial burden that incontinence places on people who are already vulnerable because of their disease and disability. See case studies 4 and 5 for examples.

Case Study 4: Considering returning to work so she can provide herself with the products she needs to maintain social continence

M is a 55-year-old woman with bowel cancer. M is on a disability pension. She was diagnosed with carcinoma of the bowel in January 2000, for which she had radiation treatment that resulted in faecal incontinence. If symptoms persist she will have surgery for colostomy in the New Year.

M uses anal plugs to control her incontinence because this allows her to move freely in the community. M receives subsidy from Northwest Community Equipment Scheme (PADP in Tasmania) which entitles her to anal plugs at half price. However, M is restricted to 2 anal plugs a week on her budget. **M is considering finding work cleaning houses to enable her to purchase more anal plugs.**

Case Study 5: Searching for someone to help pay the costs

F is an eighteen-year-old man who was born with microcephaly. He has the body of an eighteen-year-old, but his mental age is said to be that of a six-month-old baby. F receives the Disability Support Pension. F's older brother has a chronic and progressive illness and lives with them. F's parents are separated and his mother, who receives the Carer's Pension, is the main carer for F and his brother. They receive assistance from a family friend. F's father does not provide any support.

F is totally dependent for all activities of daily living. He cannot weight bear and slumps when he sits up. He has extensive equipment needs such as a padded bed, designed to prevent him from injuring himself, a lifter, and a specially constructed wheelchair that keeps him upright. He requires thickening agents for his food and drink to prevent aspiration and choking. F's mother receives respite one weekend per month and one week annually. She finds it difficult to obtain regular respite because F is unable to weight bear.

F used to wear large junior disposable nappies, which his mother extended with tape, until he was 14 years. However, these nappies (designed for toddlers) were inadequate for managing F's incontinence. She now receives nine packets of Tena Slips per month from a Public Hospital, but this discontinues soon because F is 18 years old. She will then rely on the Continence Aids Assistance Scheme for $450.00 per annum, which is far from sufficient to cover F's considerable equipment and product requirements.

F's mother is constantly tired after caring for F and his older brother. She expends a lot of energy trying to understand community support systems and identify ways she can receive the social and financial support she requires to continue caring for her family.

A further problem with the CAAS scheme is that patients with degenerative diseases, or diseases considered to be age related, are specifically barred from this scheme. For example, see Case Study 6.

Case Study 6: "Sorry, your disease is a degenerative disease'

B is a 57-year-old man with Steele-Richardson Olszewski syndrome (also known as Progressive Supranuclear Palsy or Mona Lisa disease). It is a rare cerebral degenerative disease of unknown aetiology that occurs in adulthood. B has the typical clinical signs of unsteady gait, abrupt falls, slowness, rigidity of neck and limbs, difficulty maintaining eye contact, altered speech, irritability, dementia and incontinence of urine and faeces.

B receives a Disability Support Pension. He lives with his wife who is his main carer. B's condition has meant he has had to sell his business in a small country town (approximately 300 residents) to relocate to a nearby town of 4000 residents. His wife has relied on local people to help her with his care, but this has become increasingly difficult as B weighs 120 kg. He has become increasingly difficult to manage due to his frequent falls. B receives occasional respite at the hospital.

B's wife manages his bladder incontinence with penile sheaths, drainage bags and large containment nappies, which are paid for by B and ordered via the Community Health Centre's Continence Advisor. B often pulls off the penile sheath, so nappies are being used with increasing frequency. B drinks abnormally large amounts of water due to his condition, which then necessitates increased use of nappies.

B spent approximately $1,016 last year on incontinence products and received no assistance with this purchase. His Continence Advisor, Physio and Doctor applied to CAAS (Continence Aids Assistance Scheme) but were informed B fell outside the eligibility criteria. Naturally B's wife was disappointed because the continence management is only one aspect of B's ongoing equipment needs, which include an electric wheelchair that they have purchased themselves. B's wife is attempting to fund his care from her carer's pension.

After CAAS refusal, health workers advocated for B and applied (via local politicians) to gain a one-off $450 subsidy from Options Coordination. B and his wife continue to try to stay at home, with one week in hospital and three weeks at home each month. Increasing costs and lack of subsidy are placing extra burden upon this family.

A second major problem is that costs of continence products have risen significantly, but most subsidies are not indexed to inflation and have remained static for several years. It must be remembered that incontinence products usually only represent one aspect of multiple expenses for people with chronic degenerative illness and disability. Many people are spending up to $100 per month on pharmacy expenses and have additional equipment needs as well. Because subsidies are not indexed to inflation, they do not keep up with the real costs of products.

A third problem regarding the inadequacy of current subsidies relates to patients with neurological disease. This problem surfaced repeatedly during the questionnaire.

In 1998 the Australian Quadriplegic Association surveyed 200 members who were living in the community to determine the personal cost of their disability. The data was analysed by Price Waterhouse Cooper. The survey found each person spent an average of $20/fortnight on incontinence products over and above the CAAS allowances and all other government assistance.

In February 2000 the Australian Quadriplegic Association surveyed 100 members, and 68 per cent stated their allowance did not last the full 12 months, which led individuals to restrict and modify their product usage. Of this 57 per cent ran out of allowance within 9 months or less. These individuals' supplemented PADP allowances with CAAS allowances and/or other State/Territory based schemes, however, 69 per cent stated this combined figure was not lasting as long as it had 5 years ago.

Consultants for spinal injury consumers have been asked to provide legal firms with reports on the possible equipment needs of persons living with spinal cord injuries. One nurse continence advisor from Western Australia provided us with a table, which highlights an estimate annual cost for products to provide social continence for persons living with spinal cord injury. The estimates are in the range $1,810 - $2,350 annually for bladder management and $2,627 - $3,167 for bowel management. It is recognised that CAAS was initiated as a top up to State subsidy schemes, but for many consumers this is the only scheme for which they qualify and the allowance of $450 is manifestly inadequate.

The following case studies provide some examples of people who have costs that substantially exceed their subsidy entitlement.

Case Study 7: Client contains costs but makes compromises to her health – CAAS pays $450, Consumer pays $550

Q is a sixty three-year-old woman with quadriplegia sustained after falling down the stairs of her apartment twelve years ago. She is a widow on a Disability Pension and lives alone in an independent Housing Trust unit.

Q receives thirty-eight hours of care per week from Paraplegic and Quadriplegic Association, which entitles her to three visits per day for transfers from bed to wheelchair and vice versa, showering, bowel care, meal preparation, and general house-work. She pays $1,040.00 per year for Meals on Wheels. She has a large number of medications, so her pharmacy bill is generally around $1,200.00 per year. She also meets the usual costs of rent, electricity, telephone and household insurance. In addition, Q has a security system because she lives alone, and having a disability, she feels particularly vulnerable to possible break-ins and attack.

Q manages her urinary incontinence with an indwelling catheter, which is cared for by District Nurses. Q has had a lot of problems with blocking catheters, leaking catheters and infections. A stringent regime of leg bag changes has reduced the infections, but the cost of her catheter equipment has increased considerably. Her current requirements include one $10.00 catheter per month, one $10.00 leg bag per week and six bisalax enemas costing $3.30 per week. Additionally, she requires sundry items for bladder management and skin care to a cost of $20 per month, bringing her continence product costs to approximately $1,000 per year. Consequently the $450.00 per annum Continence Aids Assistance Scheme allowance is insufficient and she must find the balance from her pension.

$450, Consumer pays $750

C is a 29-year-old man with cerebral palsy. C is on a Disability Pension. C has intellectual disability and has been de-institutionalised since 1990. He lives in a group home with four residents under the Disability Services Program. C attends Day Care from 9.00 a.m. to 3.00 p.m.

C controls his bladder and bowel incontinence with containment pads. He has undergone an extensive bowel and bladder management program over the last 12 months, which involved charting, pad weighing, and specialist regimes allowing pad use to be reduced to three per day.

C contributes $500 per month to his housekeeping, which leaves him with approximately $220 for his personal use, which includes purchasing incontinence products. Three of the residents require continence management and consequently they "Rob Peter to pay Paul" until all their resources have been depleted. **His costs remain approximately $1,200 per year but C receives the $450 CAAS allowance, so his personal expenses are approximately $750 per year.**

Case Study 9: CAAS insufficient- local hospital has supplemented costs, but can no longer economically sustain this assistance

Y is a 16-year-old Indigenous Australian woman who has bladder incontinence after developing a spinal epidural abscess at age four years. The abscess caused spasticity in her lower limbs and she also developed a neurogenic bladder. Y has a dilated left ureter. Y lives in a remote settlement of 150 people, which has a health centre staffed by nurses, and visited by a doctor once per week. The nearest hospital is 1.5 hours away by car.

Y wears nappies during the day and nights, which were previously supplied by the local hospital, but the hospital could not sustain this assistance due to the cost. The family now purchase nappies via a pharmacy, which sends them out to the settlement. Y's parents receive a Disability Support Pension. Y's mother is her main carer with other family members helping at times. The living conditions are basic and there is no phone.

Now that Y is 16 she has applied to CAAS who have supplied nappies for part of the year, but the amount is inadequate for her continence needs.

In addition to the problems encountered with the CAAS scheme, the Program of Aids for Disabled People (PADP) also varies widely across the different states. Different administration, eligibility criteria, types of product assistance, and subsidy amounts are seen, creating inequity between states and territories with regard to continence products.

The basis problem is that PADP schemes which have different names in each state, has different subsidy amounts creating inequity between states and territories. Therefore, people with the same disability and need for incontinence products receive different amounts of subsidy in each state/territory. Such inequity creates difficulties for national consumer groups with members in each state and territory experiencing different scheme regulations. Examples from Tasmania and South Australia are shown below.

Variations in PADP Subsidy in Each Australian State and Territory

Northern Territory	$1,500/year
Victoria –	$1,200/year
Tasmania	$1,000/year (client pays half of total bill up to $1,000)
ACT	$1,000/year
New South Wales	$ 800/year (currently under review),
Queensland	Unstated
South Australia	$ 450/year
Western Australia	No incontinence products allowed

Case Study 10: Incontinent for 21 years post-surgical complications

CES (PADP Tasmania) pays $500; consumer pays $1,350 per year

L is a 71-year-old woman with bladder and bowel incontinence following nerve damage during spinal surgery at age 50 years. L was an active sports woman prior to this incident. L had a permanent colostomy 12 years ago and since then has commenced clean intermittent self-catheterisation 5-6 times per day. L's colostomy supplies are subsidised via membership of a stomal association for $25 per year.

L has received instructions from her urologist to use a clean catheter each time to prevent infections. **The cost of managing her urinary incontinence over the last 15 years is estimated at $28,000, a sum of approximately $1,850 per year.** L has received a $500 subsidy for each of the last two years. L does not complain about the financial costs, claiming she is "lucky to be alive", but concedes they are an added burden on top of her disability.

Case Study 11: Chronically ill for 16 years, incontinent for 3 years – ILEP (PADP South Australia) pays $450, the consumer pays $2,400

W is an 84-year-old man, with Parkinson's disease and Dementia, which he has suffered for the past 16 years. W and his wife are pensioners. He is cared for at home by his wife, and their daughter who is on a Disability Support Pension and receives the Carer's Allowance. The last two and a half years have been marked by progressive deterioration in his conditions with hallucinations, falls, swallowing difficulties, urinary and faecal incontinence and W is now essentially bed-ridden and totally dependant in all activities of daily living.

W has an extensive medication regime administered via the gastrostomy tube by which he is fed six times per day. He requires regular pressure area care and wound care to a pressure sore on his heel. The District Nurse, his wife and daughter, are his full-time carers and direct his incontinence management. W receives Domiciliary Care respite service for seven hours per week and is currently on the waiting list for showering assistance. The local council has recently commenced fortnightly house cleaning.

Managing W at home has necessitated much equipment (hire and/or purchase) such as a wheelchair, shower chair, commode chair, lifter and now a hospital bed. The family receives 7 single long sheets and 10 Kylie sheets (washable absorbency pads that protect furniture and mattress) per week from Domiciliary Care.

W's incontinence is managed using penile sheath drainage and disposable pads used on alternate days. He sometimes requires up to three sheaths per day, because when he is confused he pulls them off. Each sheath costs $1.80. The Independent Living Equipment Program (ILEP) provides thirteen sheaths; one leg bag and one overnight bag per month and the family purchase the rest. The pads cost $74.00 a box and each box lasts approximately three weeks. **W pays around $2,400 per year on incontinence products receiving no assistance with this purchase.** In addition W requires in excess of $1,200.00 per year on medications and other pharmaceuticals.

Despite the heavy financial and social cost of W's care, his daughter says it is a "labour of love". Increasing costs without subsidy are increasing the burden upon this family.

Finally, many consumers have to apply to multiple organisations for assistance to manage their incontinence as already shown in Case Study 5. This does not promote personal dignity, or system efficiency. Most schemes are rigid and inflexible. Applicants are required to complete multiple forms containing multiple questions to access the various subsidies. Furthermore, most application forms bring with them the need to undertake a review by a health professional. This can be a cause of frustration for people with long-term static product requirements.

Appendix C – Sutherland Hospital Information Package

Incontinence: What's the cost?

Development of a Framework for Economic and Cost Evaluation for Continence Conditions

The Sutherland Hospital and Community Health Service

Development of a Framework for Economic and Cost Evaluation for Continence Conditions

Background

- Australia faces challenges in providing efficient and effective health services. The ageing population presents a shift in focus towards conditions associated with older persons, including continence conditions and dementia. The question of how best to organise and fund health care delivery to respond to these challenges is paramount.
- The real cost of continence conditions is unknown within the health service. Cost identification and allocation of resources in the acute setting is highly dependent on the prevalence of the condition as documented by the clinicians, therefore unless incontinence is specifically recorded, it is not coded and consequently no additional funding is allocated.

Purpose

- The project aims to identify how to determine the costs of incontinence; this will provide a framework for cost analysis that can be utilised in subsequent trials.
- Analysis of the direct costs of urinary and faecal incontinence will provide economic data that will allow scarce resources to be allocated most appropriately to provide the maximum amount of benefit to those involved.

Who is involved in the study?

- This study was initiated by the UNSW, in collaboration with St. George Hospital, The Sutherland Hospital and Community Service and Port Kembla Hospital.

The Sutherland Hospital and Community Service's role in the study

- This is a pilot study, Sutherland's involvement is very important, the data gathered from Sutherland will assist in the development of a continence cost analysis framework for future studies, and this may lead to increased funding and service provision.

Why was Sutherland Hospital and Community Service chosen as a pilot site?

- Sutherland hospital was chosen because of its identified interest in continence and the well organised Aged Care services that allow for easy access to patients/clients.

Method

- **Which wards are involved?**
- 4 East and Killara

- **How are patients selected for the study?**
- The Project Nurses; Marilyn Gibson-Jones and Lee Wells will identify 20 consecutive patients (i.e. as admitted) on each ward with a urinary or faecal incontinence condition and commence them on the study.

- **Inclusion criteria for the study**
- Urinary Incontinence: Two or more episodes of urinary leakage in a 48 hour period
- Faecal Incontinence: Two or more episodes of rectal leakage in a 48 hour period not associated with enema administration.

- **How will the costs of incontinence be determined?**
- For patients on the study, Staff will document on the BLUE Data Collection Form, all aspects of care relating to continence issues,

This vital data will enable the study to examine:

- The direct cost and extent of urinary and faecal incontinence as it currently exists, in terms of:
- prevalence.
- staff costs.
- intensity of care required.
- material expenditure.
- investigations.
- treatment.
- Particular attention will be paid to comparison of relative costs and subsequent benefits of different forms of treatment and management.
- Within Sutherland Hospital, individual attention will focus on frail older persons, particularly males and incontinent patients with dementia and/or neurological disease.

- **How long is a patient on the study?**

Each patient must have the BLUE Data Collection Form completed for the length of their stay. Patients transferred in from other wards will not be included. The study will cease if a patient is transferred out to another ward. Patients who are medically stable and have a very long length of stay may be taken off the study. The criterion for this is yet to be determined.

- **Special note for Killara Staff**

- The Project Nurse will note the patient's FIM score, on admission and discharge on the back of the Blue Data Collection Form.

- **How long will the study take?**

- It is hoped that the data for the 20 patients on each ward will be collected before the end of December and initial costing feedback to the wards early 2001.

We must make sure that the cost analysis from this project accurately reflects what we do
Thank you in advance for your commitment and enthusiasm

Guidelines for the Continence Costing Study

What is your role in this study?

Your role is pivotal to this study. Never before has such a study been undertaken. We don't know how much nursing time or money is currently being spent on incontinence in this hospital or any hospital for that matter. This is a very exciting study and your participation is vital.

1. At the beginning of your shift identify which of your patients are on the study. Each patient on the study will have an ARMBAND with a BLUE piece of paper with STUDY written on it.
2. Each patient on the study will have a blue form enclosed in a BLUE FOLDER hanging at the end of his or her bed. Killara patients will have a dark blue dot on their folders.
3. The form has several keys, which you will need to study to gain an understanding of the form. Take time to study the blue form.
4. The study aims to find out how much we spent on incontinence in regard to staffing and equipment used. The data obtained from the blue form aims to provide this information so accurate documentation is of the essence.
5. A record needs to be made on the blue form each time you attend to a patient for continence issues: toileting, pad changes, bed changes, catheter care etc.
6. You will find sample scenarios in your Folder. Please ask the In Charge of Shift where you can locate this folder.
7. Marilyn Gibson-Jones will be the Project Nurse for this study and will be available Monday – Friday mornings to answer questions regarding the study.
8. On weekends Lee Wells will be available to answer any questions you might have regarding the study.

Good luck everyone. Do your best, that's all we ask.

Appendix D – Blue Sheet

Table 44 **Blue Sheet for the Development of a Framework for Economic and Cost Evaluation for Continence Conditions**

V = Variation any variations please comment overleaf. Document all time associated with Incontinence.

Date & Time	F = Faecal U = Urinary B = Both	Toilet Assist Time	Pad change		Bed change		3 day Flow Chart Time	Bladder Scan Time	U/A MSU		P/R Time	Catheter IDC SPC		Drainage System		Number and Designation of Staff	Total Time
			Key	Time	Key	Time			Test	Time		Key	Time	Key	Time		
08.00																	
09.00																	
10.00																	
11.00																	
12.00																	
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05.00																	
06.00																	
07.00																	
Total Time =																	

Appendix E – Cost Master Sheet

Table 45 Cost Master Sheet

Sutherland Rehabilitation

Patient ID	Sex	Age	Patient subgroup	LOS (days)	Total Cost $	Total Consumables average daily cost $	Total staff average daily costs $	Total time (minutes)	Total Cost $ (faecal)	Total staff average daily cost $ (faecal)	Total consumables average daily costs $ (faecal)	Total Cost $ (urinary)	Total staff average daily cost $ (urinary)_	Total consumables average daily costs $ (urinary)	Total Cost $ (urinary & faecal)	Total staff average daily cost $ (urinary & faecal)_	Total consumables average daily costs $ (urinary & faecal)	No. of bladder scans	No. of mid-stream urine tests
SUKI01	M	85	3	10	43.88	4.12	39.76	101.00	0.53	0.53	0.00	36.66	33.45	3.21	1.26	1.15	0.11	2	2
SUKI02	F	80	1	21	44.60	5.29	39.31	101.00	1.06	0.97	0.09	25.79	22.55	3.23	10.38	9.00	1.38	0	2
SUKI03	M	72	4	11	36.06	5.55	30.51	78.00	2.67	2.61	0.06	23.37	18.92	4.44	0.00	0.00	0.00	1	1
SUKI04	F	98	1	12	36.38	2.60	33.78	85.00	0.00	0.00	0.00	27.13	24.86	2.27	2.59	2.49	0.10	0	0
SUKI05	M	38	5	2	16.66	3.07	13.60	32.00	0.00	0.00	0.00	10.54	7.48	3.07	0.00	0.00	0.00	0	0
SUKI06	F	84	1	21	66.50	6.71	59.79	157.00	0.90	0.47	0.42	53.89	48.97	4.91	6.68	5.74	0.94	4	3
SUKI07	M	78	3	14	52.43	10.57	41.87	112.00	14.49	13.47	1.01	23.90	18.10	5.80	6.66	4.56	2.10	0	0
SUKI08	F	91	1	12	44.30	7.29	37.01	94.00	0.00	0.00	0.00	33.10	27.89	5.21	5.49	3.95	1.54	0	0
SUKI09	F	86	1	20	39.48	4.07	35.40	93.00	0.80	0.74	0.06	27.46	24.91	2.56	5.39	4.59	0.81	1	0
SUKI10	M	76	3	11	48.17	6.88	41.29	109.00	6.08	5.60	0.48	35.80	31.34	4.46	3.14	2.27	0.87	0	0
Total		788		134	428.46	56.15	372.32	962.00	26.53	24.39	2.12	297.64	258.47	39.16	41.59	33.75	7.85	8	8
Mean		78.8		13.4	42.85	5.62	37.23	96.20	3.79	3.48	0.30	29.76	25.85	3.92	5.20	4.22	0.98		

Appendix F – Additional Notes on Hostel Residents

By Jan Swinfield

Case 1

The first patient I conducted a DBICI for, at Thomas Holt Village, was an interesting lady who is 84 years old. She gets all her pads from PADP and knows to dispose of them in the appropriate sanitary bin so they are disposed of properly. She has a dislike for taking any kind of medication, whether it is for diarrhoea or constipation. Her theory is that medications give her diarrhoea and everything has to be "natural, natural or natural!" She suffers from general leaking all the time, not particularly stress, just general leaking.

On the DBICI report that I conducted on her, she told me she uses only about 5 pads a day, however when I looked into this, she actually had bits and pieces of pads, wrappers and the peel off paper used with adhesive pads all over the room, so if a visitor was to sit down, they were likely to have a pad adhere to them also! She uses Incohelp and Depend but when I cross-referenced it with the blue sheets, she is actually probably using more like 10 pads per day. Where she says she is independent, she is not. She always needs help. She is probably a little bit confused at times. She also told me that she NEVER (!) wets the bed, however according to her blue sheet; she does, so I do not think it is a deliberate ploy on her part not to give me the information, as she was really co-operative. It is probably due to the fact that she is a little bit confused, or may not remember exactly what she has done before. She has also done pelvic floor exercises before and she is a bit of a "hip old granny" which would sum her up well.

Case 2

The next patient I did the DBICI with was a very demanding patient who requires a lot of time, a lot of repetitive nursing care, which she does not actually need but is probably due to a lack of attention that she is craving. She is probably a lot more incontinent than the other ladies that I have seen.

She has a sad history with breathing problems with asthma, but she actually had a hysterectomy when she was 20 years old after giving birth to her first baby girl, however the baby girl died at three weeks of age with a leaking heart valve. This led to the demise of her marriage so she is a little bitter about that and carries the scars of that to this day. She also suffers from bowel cancer, diagnosed nine years ago. Apparently, she has seen numerous specialists in previous years for her bowels and her bladder and has had many MSU's. The reason for her hysterectomy was that she had very heavy periods and bled for seven days with a week between each "period ". This apparently went on for three years and her doctor performed a total hysterectomy so she had no other children.

She leaks a lot and apparently floods all day but she only states that she uses 6 pads per day, usually wearing a Depend (large.) This lady does not appear to be confused, just needing a little extra attention and understanding. However because of lack of staff time she probably doesn't get what she needs i.e. someone to talk to. She also wets her underwear, her bed, and the chair. She suffers from constipation from time to time and is supplied by PADP for her pads. She states she uses only 6 pads per day but it is probably more than that in actual fact. She also knows how to dispose of them properly. She also told me that if I ever needed to know anything else that she would be very willing to talk to me just for the sake of having a visit.

Case 3

The next patient I visited is a very active 91 year old, very independent. She is in very good physical condition. She uses Incohelp and probably uses one to two a day and is supplied by PADP. She also uses pieces of rag material i.e. cut up old underwear, old face cloths etc. but she handles it all herself. If she didn't use the other bits and pieces she would probably use about 3 pads per day but she is a very clean and tidy lady and takes care of herself. She has had numerous MSU's, which have all been negative.

It is interesting to note that even though PADP supply her with pads, she tries to cut down the cost that they would bear by supplementing and hand-washing the face cloths etc. herself, even though she isn't paying for the pads. She is quite a cost conscious lady. Her main problem is frequency. She has to get up twice at night. She doesn't require help and she also knows where to put the used pads and they go in the appropriate bin.

General Comments

Many of the patients at Thomas Holt Village have dementia thus making it difficult to conduct DBICI's. I will attempt this however in the hope that the patients will offer some factual information in retrospection. This can sometimes happen when time is taken to talk to such patients.

Generally the information gathered from my hostel visits indicates that the reasons for residents entering nursing homes and hostels have nothing to do with their incontinence because half of them are incontinent in the hostel anyway and end up in the nursing homes. It is more a matter of them being old and frail, demented or debilitated, no longer coping at home and managing, general confusion, strokes etc. but not incontinence. Incontinence is not an issue. However, when they enter the nursing home, most of the staff time is taken up in dealing with the patients' incontinence but their admission is not because of their incontinence. I think a lot of the time the patients who are suffering from dementia would be continent if they had their full faculties; their incontinence is more of an issue the more demented the patient becomes. So maybe if their dementia could be treated, I wonder if this could significantly reduce their incontinence.

Appendix G – General Practitioner/Private Nursing Cost Issues

Upon reviewing the subject of incontinence in general practice, certain issues are already well known. For example, only 30 per cent of patients with incontinence seek help. Furthermore, Gunthorpe et al. (2000) showed that, using a screening test, 44 per cent of patients seen in general practice actually suffer from incontinence, but many of these do not want help. One of a group of projects (the Perth Project) studying continence management in general practice conducted a waiting room survey. This revealed that of 2,965 patients, 1.4 per cent leaked urine "always". Approximately 3 per cent leaked "often". Between 8-29 per cent leaked "occasionally", depending on the type of leak e.g. stress leak versus urge leak, 65-80 per cent said they never leaked urine.

There are two key economic questions concerning continent management in general practice. Firstly, is there an effective early intervention for the two thirds who do not seek help, some of whom will progress inevitably towards expensive treatments later in life? Secondly, is there a cost effective method for early intervention in these patients? The answers to these questions are not known, in any of the world's literature, as shown in First Progress Report (literature review section).

To gain some understanding of these questions, we studied three Continence Care Model Projects. These were funded in 2000 as initiatives of the National Continence Management Strategy (NCMS). The aim of these Projects was to develop a coordinated and consistent approach to improving continence management in the community (e.g. general practitioners' surgeries, pharmacies and continence clinics). Training and resources were provided to primary care providers including general practitioners and pharmacists by the Demonstration Projects in the Hunter, North East Victoria (Wangaratta) and Western Australia (Perth). The purpose of this was to enable primary care providers to manage and treat incontinence appropriately. Education was provided by NCAs to doctors and pharmacists in the hope of increasing the detection and early treatment of incontinence in community dwelling patients.

The projects, which were of twelve months duration, involved in-service training for health professionals and pharmacy staff. The project team distributed information and resources at various contact points such as community health centres, women's health services, support groups pharmacies, GP surgeries, council offices, libraries as well as hospital waiting rooms and rehabilitation clinics. Outcomes of the projects were assessed internally by informal feedback through stakeholders, by the Commonwealth government in line with the NCMS and independently by an evaluation team from the University of Newcastle.

Reports from the three Demonstration Model Projects were reviewed for any information about costs incurred during the projects.

The Wangaratta Project recruited 123 pharmacy staff and 46 health professionals in a project area with an estimated population of approximately 160,500 and an estimated 8,000 people that needed to be targeted for improved continence management (using a figure of 5 per cent of total Australian population with incontinence according to CFA figures). The project reported a 50 per cent increase in new clients with incontinence over the first 6 months (compared to the previous 6 months before the project commenced). Because the project did not have an economic component, it was not possible to ascertain from the project report any costs of interventions and measurements of improved outcomes.

A number of coordination and information issues and costs were raised in the report from the Wangaratta Continence Project. First, a small amount of funding (this amount was not specified in the report) was made available for additional salaries for allied health workers in continence clinics (on the basis of areas of need in the same way as Diabetes Educators operate in GP practices). Second, the fees policy adopted by Divisions of GP meant that unexpected additional costs were incurred during the project. Additional fees at double the budgeted rates were invoiced to the project by GPs for their attendances at steering committee meetings in addition to the budgeted training workshop attendances. These are important considerations in costing for collaborative arrangements with Divisions of GP, obviously GPs feel that they are overworked and underpaid. They are unable or unwilling to embark upon any new projects without substantial remuneration.

If information on the management of incontinence in the GP setting is difficult to obtain, perhaps one should ask "is such information really necessary?". The authors believe that such information would be important for the following reasons:

Firstly, such information would provide further information about the "burden of disease". The authors suspect that GPs find history taking and physical examination of incontinent patients a time consuming task which is not properly remunerated under the current Medicare system. It would be useful to ask a sample of GPs to carry out continence assessment and measure the time taken to do so: they would probably "lose money" by doing continence assessment, rather than other activities such as child vaccinations.

Secondly, because GPs are not well remunerated for continence care, it is believed that they do not actively seek out the problem. GPs place higher priority upon management of hypertension, heart disease, childhood vaccinations, pap smears etc. which are more likely to prevent death. However, with the rising proportion of elderly in the population, issues such as incontinence will consume an increasing amount of the health care budget. Efforts should be made to find ways of encouraging GPs to diagnose and treat incontinence before it becomes severe and costly.

A separate cost issue was noted by the Project team. Pharmacies tended to stock two proprietary brands of continence aids. Problems arose if a Continence Nurse Adviser suggested alternative brands as being more suitable or cost-effective for a client or if the products were not listed on those eligible for government assistance. A proposal by the Guardian Pharmacy Guild with the Royal District Nursing Service to set up a collaborative provision of a Child Enuresis Clinic in Melbourne pharmacies was abandoned as a non-viable business proposition. Hence several economic problems were evident in this pilot study.

The Continence Care in the Community (CCC) in Perth recruited 88 general practitioners, 88 physiotherapists and 28 nurse continence advisers. General practitioners were reluctant to participate in the program due to lack of staff. This project was unable to recruit pharmacists. There was considerable difficulty in engaging pharmacists in the collaborative process due to the concern pharmacists had with maintaining a competitive edge with other suppliers of continence aids (supermarkets) and the narrow margins of profit they struggled with in allocating floor space for displaying relatively "cheap" products such as pads.

The Western Australian report provided details on the average number of hours worked per week, the number of clients seen and the types of services and frequency offered by the physiotherapists and nurse continence advisers, before and after the intervention. Physiotherapists experienced a decrease in both number of hours worked per week from 20 hours before the intervention to 17.7 hours after the intervention, and the number of clients seen, from 13 patients per week to 10 clients per week after the program was instituted. Conversely, nurse continence advisers increased the number of hours worked per week from 26 hours to 28 hours per week with an increase in the average number of clients seen per week from 12 to 15 per week. More clients were self-referred as well as through GP referrals.

Resource and cost issues raised in the Western Australian report highlighted the need to consider the resource and cost implications from the view of different stakeholders. Information on costs incurred in providing care for continence conditions in general practice is lacking. The types of cost items required for economic evaluations of interventions provided in general practice include overhead costs, salaries of staff providing the services (nurse continence advisers, pharmacists, and physiotherapists), training and educational programs including the costs of paying general practitioners to attend such workshops. Additional costs include the opportunity costs incurred in the provision of continence aids by private providers such as pharmacists who may not necessarily display and sell the most economically effective continence aids to patients. Further economic work is needed to support decision making in this area. Considering labour costs constitute a major consideration in any program budget, changes in staff resources on a larger scale need to be carefully examined.

Private Nursing Services

We collected data on the types of services offered and the charges levied by a sample of six private nursing services, three from the St. George area and three from Northern Sydney area. These services were listed as recommended private nursing agencies by Southcare at Sutherland Hospital and the Royal North Shore Hospital Community Rehabilitation and Geriatric Services.

In addition to providing continence assessment and management, catheter and colostomy management, education and support, these agencies provided nursing assessment, case management and coordination, post acute care, hospital in the home, wound and medication management, IV therapies, aged care, diabetes management, palliative care and personal care for hygiene. Personal hygiene care is usually provided by Assistants in Nursing. Catheter and Colostomy management are provided by Enrolled and Registered Nurses. The frequency of services varied, ranging from thrice weekly for

personal hygiene care such as showering, bed clothes and linen changing, weekly for catheter care to monthly visits for colostomy management.

There are two fee structures used by these agencies:

1. Hourly rates for Registered Nurse home visits with repeat visits generally of one hour duration. Hourly rates ranged from $38 to $46.50 on a weekday, $53 to $72 on a weekend and $95 on public holidays.

2. Hourly rates for three levels of staff as shown in the following tables:

Table 46 Agencies providing Private Nursing Services

Agency 1

	Assistant in Nursing	Enrolled Nurse	Registered Nurse
Weekday	23.75	29.50	38.00
Weekday night	26.25	31.00	42.00
Saturday	32.50	40.00	53.00
Sunday	37.50	44.50	79.00
Public holiday	50.00	60.00	95.00

Agency 2

	Assistant in Nursing	Enrolled Nurse	Registered Nurse
Weekday	26.12	31.79	46.50
Weekday afternoon	28.26	35.12	51.38
Weekday night 11pm.-7am	29.40	35.79	52.35
Saturday	35.06	42.68	62.43
Sunday	40.53	49.35	72.18

Rebates of $12 – $15 per visit are available from private health insurers. These agencies also provide services for those patients who are covered by DVA or HACC package programs – in these cases, there are no out-of-pocket costs for the patients. Three of the six agencies reported that about 80-85 per cent of their clients belonged to the DVA and HACC schemes and therefore faced no out-of-pocket costs.

This limited survey of private nursing costs indicates that while the costs of private nursing care can be substantial and borne largely by the patients, most are heavily subsidised through the DVA and HACC services.

Appendix H – Subsidiary Tables and Figures for the SNAP study

Table 47 Bowel Management Score on Admission by Case Type

Bowel management Score	Rehab		GEM		All	
	Number	Percentage	Number	Percentage	Number	Percentage
1 (complete dependence.)	634	8.7%	177	8.3%	811	8.6%
2	203	2.8%	98	4.6%	301	3.2%
3	222	3.0%	115	5.4%	337	3.6%
4	266	3.6%	92	4.3%	358	3.8%
5	456	6.3%	183	8.6%	639	6.8%
6	1806	24.8%	516	24.2%	2322	24.7%
7 (complete independence.)	3703	50.8%	947	44.5%	4650	49.4%
Total	7290		2128		9418	

Table 48 Bowel Management Score on Admission by Episode Type

Bowel management Score	Inpatient		Same Day Admitted		Outpatient		Community	
	Number	Percent	Number	Percent	Number	Percent	Number	Percent
1 (complete dependence.)	706	10.4%	14	3.2%	32	3.2%	59	5.0%
2	259	3.8%	7	1.6%	7	0.7%	28	2.4%
3	291	4.3%	8	1.8%	7	0.7%	31	2.6%
4	318	4.7%	4	0.9%	8	0.8%	28	2.4%
5	532	7.9%	15	3.4%	19	1.9%	73	6.1%
6	1926	28.4%	79	17.8%	121	11.9%	196	16.5%
7 (complete independence.)	2741	40.5%	316	71.3%	820	80.9%	773	65.1%
Total	6773		443		1014		1188	

Figure 12 FIM bowel management admission score by number of episodes – stroke

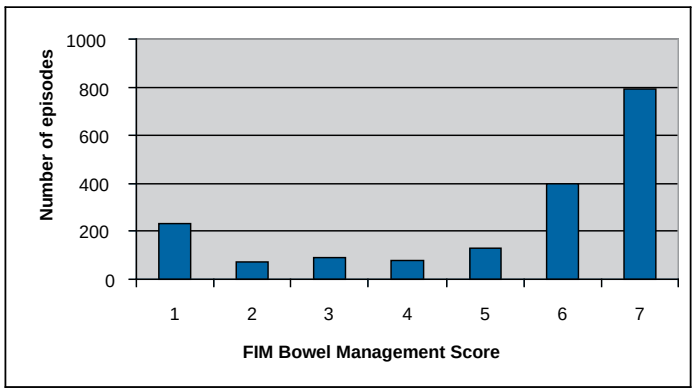


Figure 13 FIM bowel management admission score by number of episodes – orthopaedic

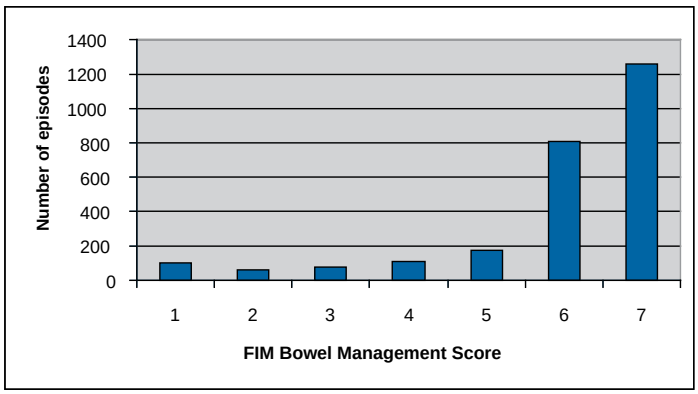


Figure 14 Bladder continence/incontinence by age group – rehabilitation patients

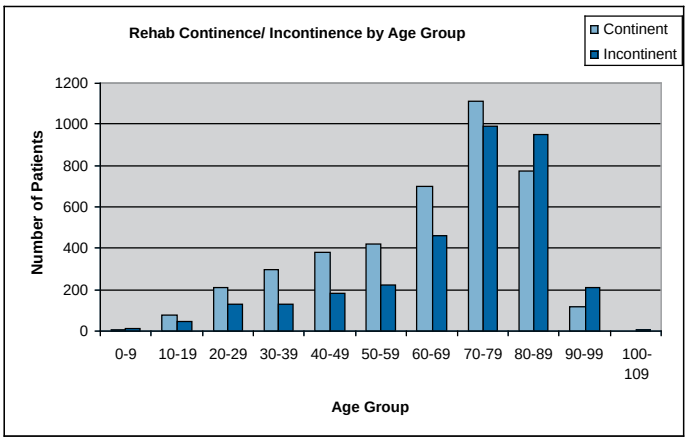
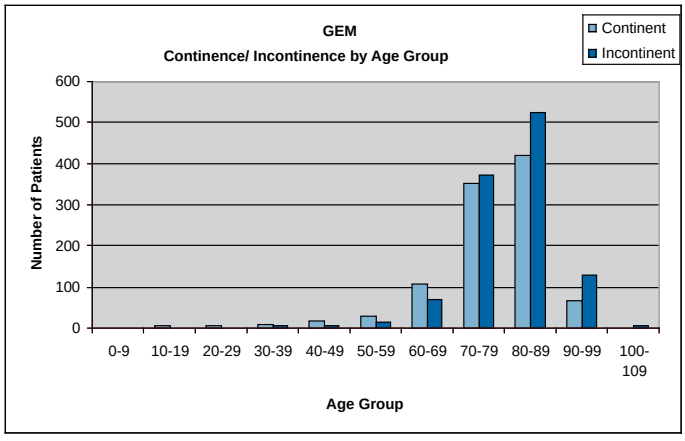


Figure 15 Bladder continence/incontinence by age group – GEM Patients



The GEM patients were generally older than the Rehabilitation patients as would be expected.

Figure 16 Bladder continence/incontinence by age group – overnight admitted patients

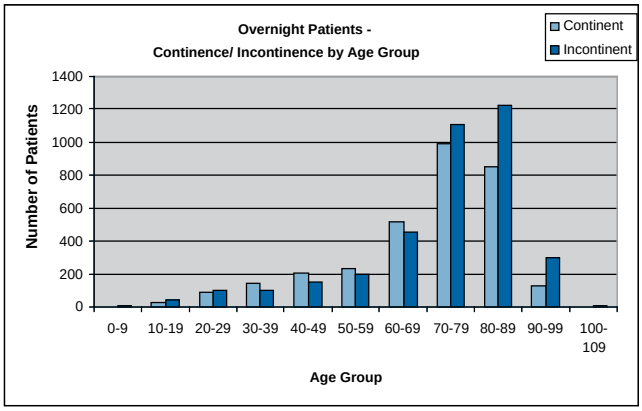


Figure 17 Bladder continence/incontinence by age group – same-day admitted patients

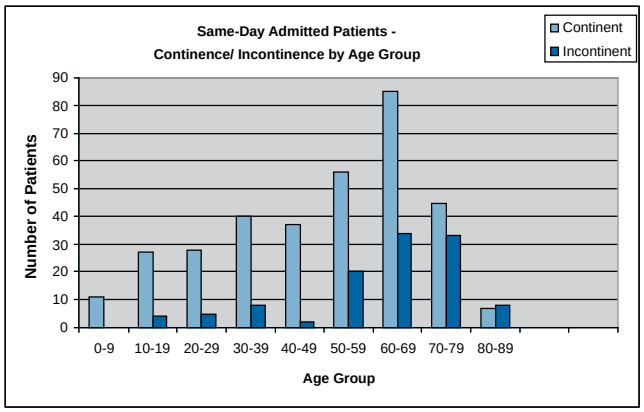


Figure 18 Bladder continence/incontinence by age group – outpatients

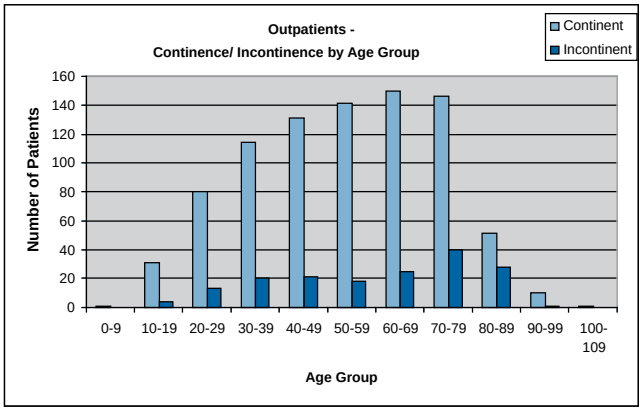
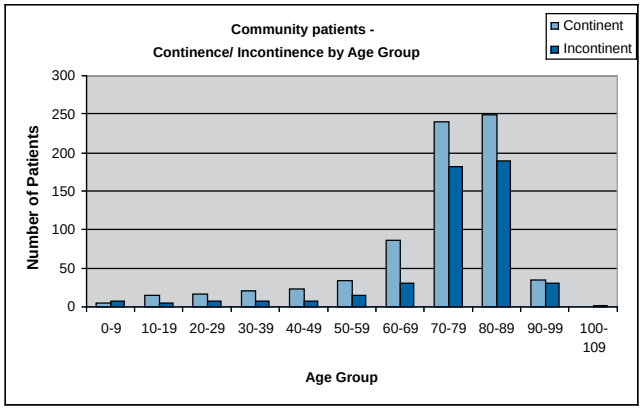


Figure 19 Bladder continence/incontinence by age group – community patients



The overnight admitted inpatients were far more likely to be incontinent

Table 49 T-Test for Difference between Means for Stroke Patients

Case Type	Episode Type	Continence Status	Number of Episodes	Average Per Diem Cost	p-value for t-test
Rehabilitation	Overnight	Continent	437	$256.28	.000*
		Incontinent	760	$291.11	
	Same Day	Continent	73	$128.10	.630
		Incontinent	36	$134.77	
	Outpatients	Continent	136	$83.70	.694
		Incontinent	41	$80.55	
	Community	Continent	39	$87.82	.520
		Incontinent	23	$96.28	
GEM	Overnight	Continent	8	$173.25	.097
		Incontinent	63	$237.11	
	Same Day	Continent	44	$92.65	.540
		Incontinent	9	$86.20	
	Outpatients	Continent	6	$77.40	.970
		Incontinent	3	$76.44	
	Community	Continent	42	$64.14	.105
		Incontinent	52	$74.75	
Overall			1772	$223.60	

* Difference is statistically significant at 5 per cent level

Table 50 Correlations between pairs of variables relevant to cost

	Cost per day	Age	Cognition Score	Motor score	Cognition change	Motor change	RCI behaviour	Bladder Continence status
Cost per day	1	-.146	-.197	-.250	.031	-.060	.088	.174
Age	-.146	1	.000	-.089	-.119	-.127	-.019	.133
Cog Score	-.197	.000	1	.486	-.416	.028	-.189	-.390
Motor score	-.250	-.089	.486	1	-.078	-.238	-.118	-.577
Cog change	.031	-.119	-.416	-.078	1	.451	.031	.102
Motor change	-.060	-.127	.028	-.238	.451	1	.007	.073

RCI behaviour	.088	-.019	-.189	-.118	.031	.007	1	.122
Bladder Continence status*	.174	.133	-.390	-.577	.102	.073	.122	1

* Continence status (Cont status) was scored as 0 representing continent and 1 representing incontinent

1. Were the average daily costs of incontinent patients significantly different from the cost of those with no incontinence problem? Independent samples t-tests were conducted within each Case Type/Episode Type group to test for differences in average daily costs between orthopaedic patients with a continence problem and those without. The results are shown in Table 51 below. As before, a statistically significant difference does not imply that it is caused by the incontinence as there could be many other differences between the groups (e.g. age, other FIM scores, etc.).

Table 51 T-Test for Difference between Means for Orthopaedic Patients

Case Type	Episode Type	Continence Status	Number of Episodes	Average Per Diem Cost	p-value for t-test
Rehabilitation	Overnight	Continent	1095	$223.72	.000*
		Incontinent	957	$242.33	
	Same Day	Continent	34	$144.54	.039*
		Incontinent	16	$215.15	
	Outpatients	Continent	185	$58.18	.197
		Incontinent	22	$68.33	
	Community	Continent	58	$62.13	.218
		Incontinent	11	$72.98	
GEM	Overnight	Continent	33	$129.03	.001*
		Incontinent	87	$180.90	
	Same Day	Continent	5	$76.51	Too few episodes
		Incontinent	2	$99.09	
	Outpatients	Continent	1	$92.86	Too few episodes
		Incontinent	1	$68.33	
	Community	Continent	39	$81.46	.409
		Incontinent	15	$91.05	
Overall			2561	$205.85	

* Difference is statistically significant at 5 per cent level

Significant differences in daily costs between the continent and incontinent groups were found in the Overnight GEM and Rehabilitation groups as well as the same day rehabilitation group.

2. Which variables contribute to the overall cost of treatment? Because of the highly significant difference in cost found in Table 51 for the overnight Rehabilitation patients, only those episodes were included in this part of the analysis. Correlations amongst the variables thought to be relevant to the cost of treatment were calculated. These variables included age, FIM cognitive score on admission (total of FIM items 14 – 18), FIM motor score on admission (total of items 1 – 13), change in FIM cognition score from beginning to end of the episode of care, change in FIM motor score from beginning to end of the episode of care, and RCI behaviour total as well as continence status. Correlations between these variables and average cost per day were also calculated. All correlations are recorded in Table 52 below. Spearman correlations were calculated between the continence status and all other variables. Pearson Correlations were calculated between all other pairs of variables.

Table 52 Correlations between pairs of variables relevant to cost – orthopaedic patients

	Cost per day	Age	Cognition Score	Motor score	Cognition change	Motor change	RCI behaviour	Bladder Cont status
Cost per day	1	0.035	-0.213	-0.285	-0.029	-0.027	0.132	0.103
Age	0.035	1	-0.243	-0.307	0.029	0.054	0.077	0.232
Cog Score	-0.213	-0.243	1	0.565	-0.319	-0.011	-0.369	-0.387
Motor score	-0.285	-0.307	0.565	1	-0.101	-0.386	-0.237	-0.540
Cog change	-0.029	0.029	-0.319	-0.101	1	0.333	0.060	0.103
Motor change	-0.027	0.054	-0.011	-0.386	0.333	1	0.029	0.186
RCI behaviour	0.132	0.077	-0.369	-0.237	0.060	0.029	1	0.159
Bladder Cont status*	0.103	0.232	-0.387	-0.540	0.103	0.186	0.159	1

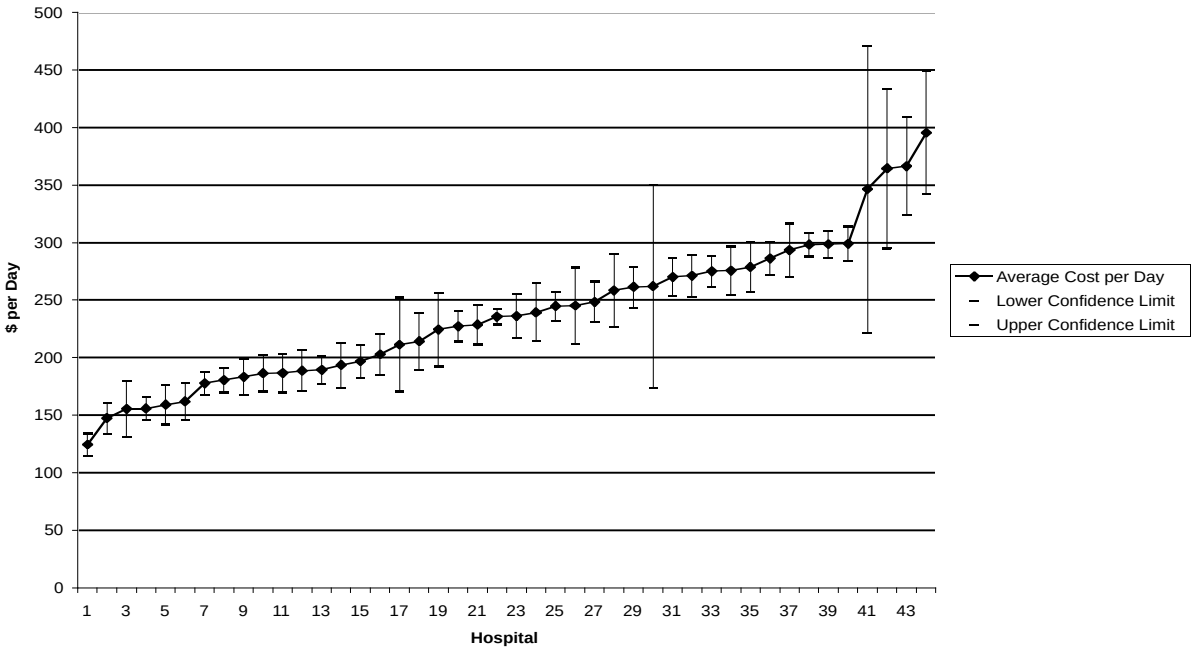
* Continence status (Cont status) was scored as 0 representing continent and 1 representing incontinent

All correlations involving the cost per day are quite low. The correlation with the FIM motor score on admission is the largest (in absolute value) with a value of –0.285. The negative value indicates that as the functional motor score increases, the cost decreases. In other words, treating patients who are more severely functionally impaired is more expensive. Correlations between the FIM cognition score and the change in cognition and between the FIM motor score and change in motor score are both negative. This is to be expected as people with higher functional scores are less impaired and have less room for improvement. There is a moderately high correlation between FIM motor and FIM cognition score (0.565).

One of the highest correlations in the table (in absolute value) is that between continence status and FIM motor score on admission. This may reflect the fact that patients who are incontinent often have other functional impairments as well.

The next step in the analysis was to model the cost per day using a combination of the other variables. The aim of this modelling was to "explain" the variability amongst costs in terms of other information, such as clinical or demographic data about the patients. Again we decided that a multilevel analysis would be the best statistical tool for this purpose for similar reasons to those described in relation to the stroke data. We found that 45 per cent of the variability in cost per day in the care of orthopaedic patients was between facilities rather than within facilities. There was a large amount of variation between average daily costs of care of orthopaedic inpatients at the different facilities represented in the database. These averages, together with their 95 per cent confidence intervals are displayed in Figure 20 in ascending order.

Figure 20 Rehabilitation Overnight Orthopaedic – Average Costs per Day at Different Hospitals



As can be seen from the above graph, the average cost per day ranges from less than $200 to almost $500.

For the multilevel analysis, rehabilitation orthopaedic inpatients only were included. The response variable was average cost per day. All explanatory variables were fitted – age, FIM cognitive score on admission (total of FIM items 14 – 18), FIM motor score on admission (total of items 1 – 13), change in FIM cognition score from beginning to end of the episode of care, change in FIM motor score from beginning to end of the episode of care, and RCI behaviour total as well as continence status. The resulting coefficients and their p-values are presented in Table 53.

Table 53 Estimated coefficients from multilevel analysis

Variable	Estimated coefficient	p-value
Intercept	237.67	<.0001
Age	-0.2586	0.0115
FIM cognition on admission	-0.5007	0.0627
FIM motor on admission	-2.3084	<.0001
Change in cognition score	-0.4491	0.2755
Change in motor score	-1.0381	<.0001
RCI behaviour score	6.9795	<.0001
Bladder continence status	-3.4709	0.2705

The estimate for the intercept indicates that the average hospital mean daily cost was $237.67 (costs are in 1996 Australian dollars). To illustrate the interpretation of the other estimates, take the FIM score on admission as an example. The estimated coefficient is –2.3084. This indicates that, if the values of all the other variables remain the same, but the FIM motor score increases by one point, the average change in the daily cost would be a decrease of $2.31.

From Table 53, it can be seen that the variables found to significantly contribute to the average daily cost of care (at a 5 per cent significance level) were FIM motor score on admission, change in FIM motor score, RCI behaviour score and age. When these variables were included, bladder continence status was found to be not significant. Including all seven variables in the model accounted for 29 per cent of the within school variation in daily cost.

3. What change in cost can be attributed to incontinence? From Table 53 we see that the estimated coefficient for bladder continence status is –3.4709. It would appear that, if the values of all other variables were to stay the same, but the patient was incontinent rather than continent, the average

daily cost of care would decrease by $3.47. Again, this result doesn't seem logical, but is similar to the result we found for stroke patients. As discussed in that Section 7.2.5.1, the result is due to confounding amongst the explanatory variables – incontinent patients tend to be older and have lower admission FIM motor scores, etc.

As stated above, to overcome this problem in a prospective data collection, there needs to be a specific data item indicating continence status. In addition, patients need to be matched on all relevant variables other than continence status. The SNAP data set used in this analysis consists of only stroke patients undergoing rehabilitation. A prospective data collection should be designed to include a greater variety of patients, including those in acute as well as sub-acute care.

Figure 21. Bowel Continence/Incontinence by Age Group – All Patients

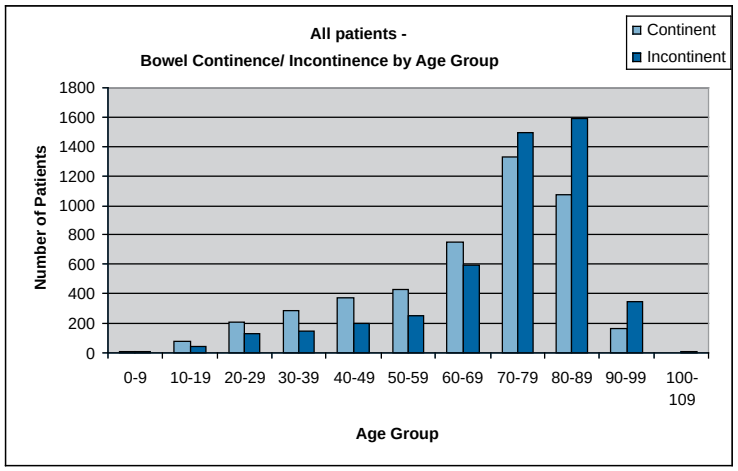


Figure 22. Bowel Continence/Incontinence by Age Group – Rehabilitation Patients

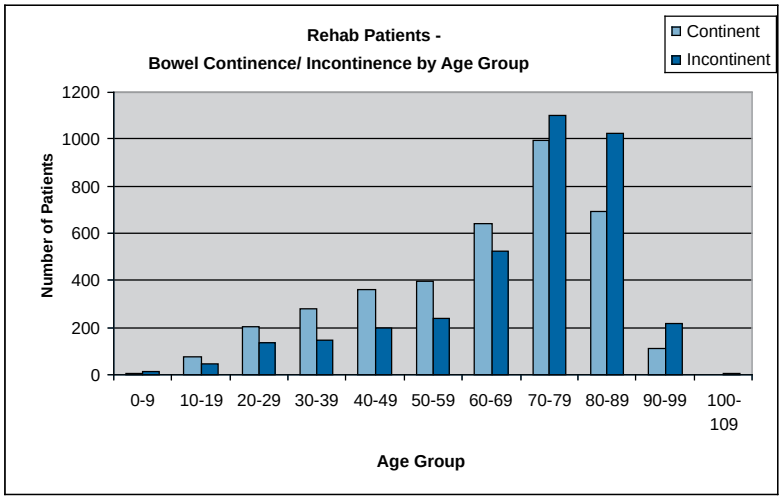


Figure 23. Bowel Continence/Incontinence by Age Group – GEM Patients

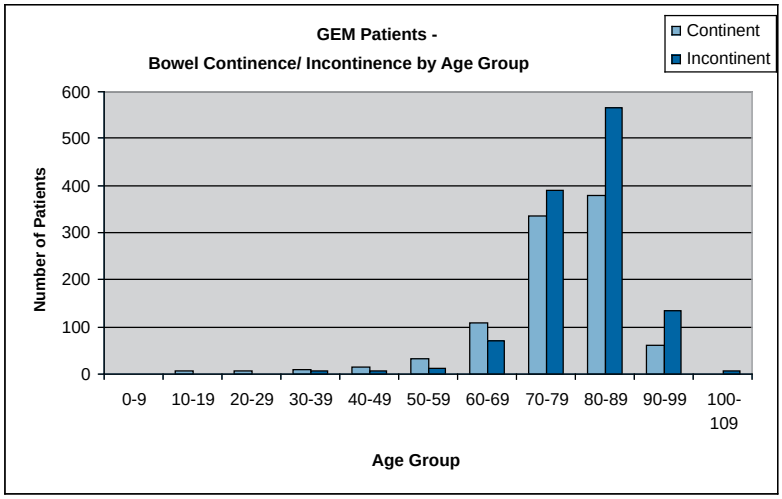


Figure 24. Bowel Continence/Incontinence by Age Group – Overnight Admitted Patients

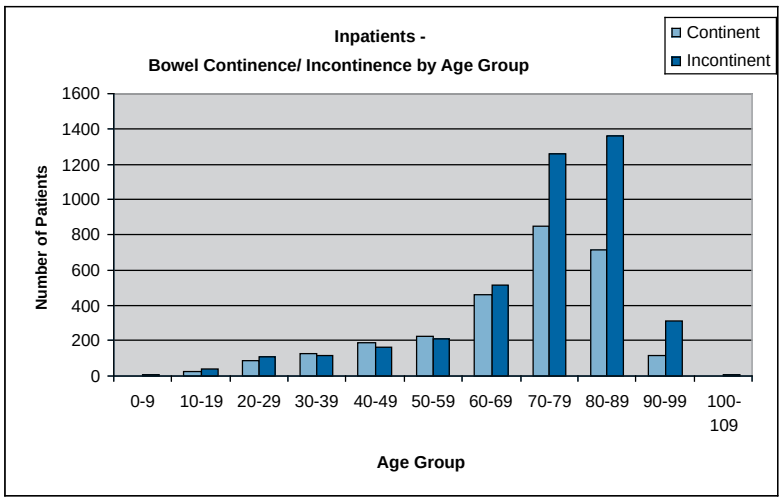


Figure 25. Bowel Continence/Incontinence by Age Group – Same Day Admitted Patients

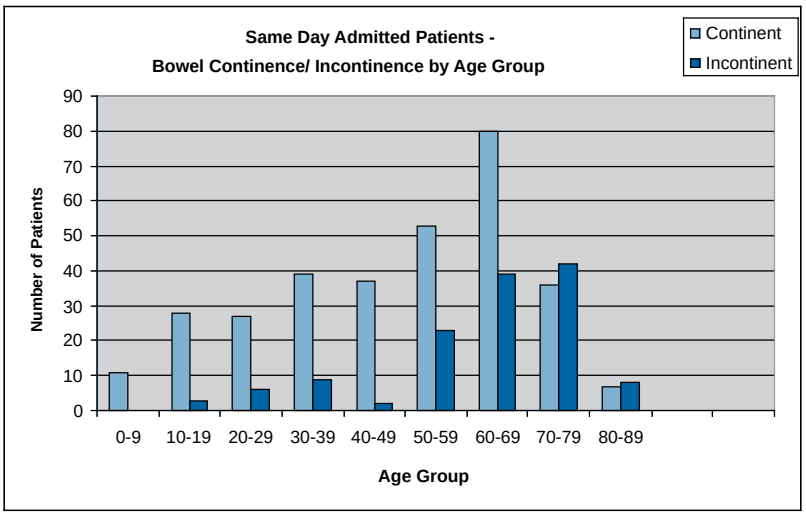


Figure 26. Bowel Continence/Incontinence by Age Group – Outpatients

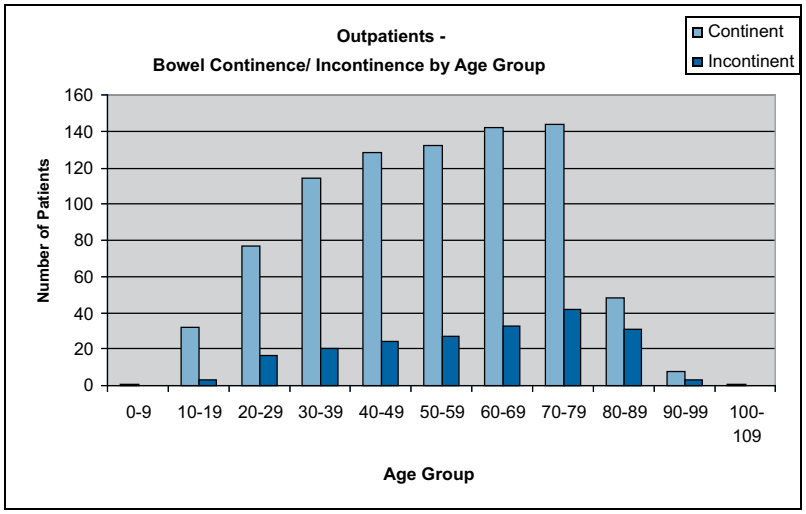
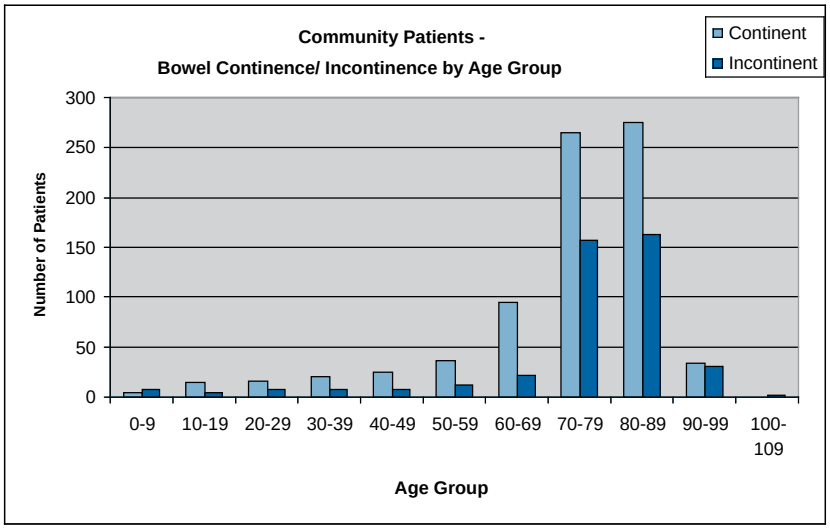


Figure 27. Bowel Continence/Incontinence by Age Group – Community Patients



1. Were the average daily costs of incontinent patients significantly different from the cost of those with no incontinence problem? Independent samples t-tests were conducted within each Case Type/ Episode Type group to test for differences in average daily costs between orthopaedic patients with a bowel continence problem and those without. The results are shown in Table 54 below. As before, a statistically significant difference does not imply that it is caused by the incontinence as there could be many other differences between the groups (eg age, other FIM scores, etc.).

Table 54 T-Test for Difference between Means for Orthopaedic Patients: Bowel Incontinence

Case Type	Episode Type	Bowel Continence Status	Number of Episodes	Average Per Diem Cost	p-value for t-test
Rehabilitation	Overnight	Continent	915	$223.02	.000*
		Incontinent	1137	$239.95	
	Same Day	Continent	32	$141.83	.034*
		Incontinent	18	$212.11	
	Outpatients	Continent	163	$59.07	.905
		Incontinent	44	$59.95	
	Community	Continent	61	$61.47	.039*
		Incontinent	8	$82.09	

GEM	Overnight	Continent	24	$115.54	.000*
		Incontinent	96	$179.41	
	Same Day	Continent	6	$85.87	-
		Incontinent	1	$65.52	
	Outpatients	Continent	0		N/A
		Incontinent	2	$80.59	
	Community	Continent	47	$83.88	.905
		Incontinent	7	$85.73	
Overall			**2561**	**$205.85**	

* Difference is statistically significant at 5 per cent level

2. Which variables contribute to the overall cost of treatment? Because of the highly significant difference in cost found in Table 54 for the overnight Rehabilitation patients, only those episodes were included in this part of the analysis. Correlations amongst the variables thought to be relevant to the cost of treatment were calculated. These variables included age, FIM cognitive score on admission (total of FIM items 14 – 18), FIM motor score on admission (total of items 1 – 13), change in FIM cognition score from beginning to end of the episode of care, change in FIM motor score from beginning to end of the episode of care, and RCI behaviour total as well as continence status. Correlations between these variables and average cost per day were also calculated. All correlations are recorded in Table 55 below. Spearman correlations were calculated between the continence status and all other variables. Pearson Correlations were calculated between all other pairs of variables.

Table 55 Correlations between pairs of variables relevant to cost – orthopaedic patients: Bowel incontinence

	Cost per day	Age	Cog Score	Motor score	Cog change	Motor change	RCI behaviour	Bowel Cont status
Cost per day	1	0.035	-0.213	-0.285	-0.029	-0.027	0.132	0.093
Age	0.035	1	-0.243	-0.307	0.029	0.054	0.077	0.202
Cog Score	-0.213	-0.243	1	0.565	-0.319	-0.011	-0.369	-0.307
Motor score	-0.285	-0.307	0.565	1	-0.101	-0.386	-0.237	-0.487
Cog change	-0.029	0.029	-0.319	-0.101	1	0.333	0.060	0.092
Motor change	-0.027	0.054	-0.011	-0.386	0.333	1	0.029	0.176
RCI behaviour	0.132	0.077	-0.369	-0.237	0.060	0.029	1	0.110
Bowel Cont status*	0.093	0.202	-0.307	-0.487	0.092	0.176	0.110	1

Continence status (Cont status) was scored as 0 representing continent and 1 representing incontinent

All correlations involving the cost per day are quite low. The correlation with the FIM motor score on admission is the largest (in absolute value) with a value of –0.285. The negative value indicates that as the functional motor score increases, the cost decreases. In other words, treating patients who are more severely functionally impaired is more expensive. Correlations between the FIM cognition score and the change in cognition and between the FIM motor score and change in motor score are both negative. This is to be expected as people with higher functional scores are less impaired and have less room for improvement. There is a moderately high correlation between FIM motor and FIM cognition score (0.565).

One of the highest correlations in the table (in absolute value) is that between continence status and FIM motor score on admission (-0.487). We believe that this is a reflection of the fact that patients who are incontinent often have other functional impairments as well.

The next step in the analysis was to model the cost per day using a combination of the other variables. The aim of this modelling was to "explain" the variability amongst costs in terms of other information, such as clinical or demographic data about the patients. We decided that a multilevel analysis would be the best statistical tool for this purpose for similar reasons to those described in relation to the stroke data. We found that 45 per cent of the variability in cost per day in the care of orthopaedic patients was between facilities rather than within facilities. There was a large amount of variation between average daily costs of care of orthopaedic inpatients at the different facilities represented in the database. These averages, together with their 95 per cent confidence intervals were displayed in Figure 19 in the Section 7.2.5.2 on bladder incontinence of orthopaedic patients.

For the multilevel analysis, Rehabilitation orthopaedic inpatients only were included. The response variable was average cost per day. All explanatory variables were fitted – age, FIM cognitive score on admission (total of FIM items 14 – 18), FIM motor score on admission (total of items 1 – 13), change in FIM cognition score from beginning to end of the episode of care, change in FIM motor score from beginning to end of the episode of care, and RCI behaviour total as well as continence status. The resulting coefficients and their p-values are presented in Table 56.

Table 56 Estimated coefficients from multilevel analysis

Variable	Estimated coefficient	p-value
Intercept	237.67	<.0001
Age	-0.2610	0.0110
FIM cognition on admission	-0.4802	0.0736
FIM motor on admission	-2.2730	<.0001
Change in cognition score	-0.4445	0.2805

Change in motor score	-1.0396	<.0001
RCI behaviour score	7.0005	<.0001
Bowel continence status	-0.7660	0.8024

The estimate for the intercept indicates that the average hospital mean daily cost was $237.67 (note that these are 1996 costs). To illustrate the interpretation of the other estimates, the FIM score on admission can be used as an example. The estimated coefficient is –2.2730. This indicates that, if the values of all the other variables remain the same, but the FIM motor score increases by one point, the average change in the daily cost would be a decrease of $2.27.

From Table 55 it can be seen that the variables found to significantly contribute to the average daily cost of care (at a 5 per cent significance level) were FIM motor score on admission, change in FIM motor score, RCI behaviour score and age. When these variables were included, bowel continence status was found to be not significant. Including all seven variables in the model accounted for 29 per cent of the within school variation in daily cost.

3. What change in cost can be attributed to incontinence? From Table 53 we see that the estimated coefficient for bowel continence status is –0.7660. It would appear that, if the values of all other variables were to stay the same, but the patient was incontinent rather than continent, the average daily cost of care would decrease by 77c. This result doesn't seem logical, but is similar to the result we found for stroke patients. As discussed in that section of the report, the result is due to confounding amongst the explanatory variables – incontinent patients tend to be older and have lower admission FIM motor scores, etc.

To overcome this problem in a prospective data collection, there needs to be a specific data item indicating continence status. In addition, patients need to be matched on all relevant variables other than continence status. The SNAP data set used in this analysis consists of only stroke patients undergoing rehabilitation. A prospective data collection should be designed to include a greater variety of patients, including those in acute as well as sub-acute care.

Appendix J – Report of Stakeholder's Workshop, Oct 29, 2001

Morning Session: Meeting of Health Economists – Discussion of First Progress Report and Constructive Criticism

Present: A/Prof Kate Moore, Dr Helen Lapsley, Dr Tessa Ho, Dr Terri Jackson, Mr Ian Brown, Ms Irenie Smoker, (Ms Angela Ingram)

Meeting commenced: 9.00am

Associate Prof. Moore gave an overview of Projects 1, 2 and the aims of the National Continence Management Strategy. The group introduced themselves. Ian Brown has 10 years as an Economist with the South Australian Department of Human Services, (including Health, Housing and Human Services.) Irenie Smoker has experience with CASEMIX, and SNAP, and had worked with the Policy Branch of NSW Health. Irenie outlined that in 1996 Prof Kathy Eagar, at University of Wollongong, had received a grant that led to formulation of the AN-SNAP classification. There were 104 sites, (99 Australia, 5 New Zealand) collecting data totalling 30,000 episodes of care over 3 months. This led to the national classification for Sub-acute and Non-Acute care (AN-SNAP). In NSW, the majority of designated sub-acute and non-acute inpatient services are currently collecting AN-SNAP data. In addition, there are some non-inpatient services (outpatient and community services) collecting AN-SNAP data.

Tessa Ho explained that Dr Chris Poulos, Director of Rehabilitation, is collecting SNAP data in Port Kembla Rehabilitation Hospital, in order to perform a "shadow" estimate of SNAP funding as opposed to historical funding. Helen Lapsley emphasised that SNAP data collection period is a "work in progress". It is important because it crosses different care settings and will become more important in the future. Irenie stated that when SNAP was initially implemented, services would submit data to NSW Health every three months. These data would be analysed, reported and discussed with the SNAP Steering Committee. This would facilitate benchmarking e.g. the average FIM per change episode, average length of stay per episode.

Terri Jackson introduced herself and outlined her experience with Community Health and Women's Health (Leichhardt) and her PhD in the late 1980's, which lead her to travel to the US to study Health Policy. In Victoria she has worked as a Health Economist, with experience costing of acute inpatient episodes of care and hospital outpatient services, including classification and costing issues. Terri described her other experience eg. Medicare Services Advisory Committee (MSAC) evaluating new technologies that receive a Medicare benefit, some of which have included incontinence treatments, so she has come to grips with outcome measures in this field. Terri outlined two of her current projects: 1. A survey of State CASEMIX classifications of their outpatient services, and 2. Positron Emission Tomography and its cost effectiveness. Tessa Ho introduced herself and outlined her clinical background in anaesthetics, subsequent Masters Degree in Health Administration, CASEMIX and funding simulation interests. Tessa mentioned her special interest in urinary incontinence because she had been a locum executive director of a division of general practice and observed GP's treating incontinence. Helen Lapsley briefly outlined her background working for Australian Medical Workforce Advisory Committee (AMWAC) for the Commonwealth Government and her interest involving projects re costs of tobacco and drug and alcohol related illness, arthritis and mental health along with an interest in incontinence conditions.

Our purpose today was to identify:

- the gaps in the data collected in the present literature
- the methodological deficiencies
- because incontinence crosses different settings and life stages, a whole range of economic models may be needed.

Helen Lapsley asked; "What can we do in the immediate timeframe of this project?"

Literature Review, described by Ian Brown

Ian explained that the review was extensive but most articles were lacking in substance as the economic content was often tacked at the end of the paper. Ian spoke about the overseas costs compared with the Australian costs; data regarding the latter was quite limited. The article by Hu worked from the "top down" which was typical of studies, with little direct patient data collection. Kate Moore, Helen Lapsley and Irenie Smoker discussed surveying patients directly and the pros and cons of that versus the need to create a theoretical model, and the hazards of extrapolation. Helen Lapsley added that not only was there a cost of incontinence in monetary terms but also in terms of pain and suffering etc. The group noted that Hu still relied on micro-economic data from the late 1980's. It was agreed that the

Pilot Studies should work from the "bottom up" in collecting data, rather than emphasising theoretical models at this stage in Australia.

With regard to Intangible Costs (i.e. loss of work productivity), Kate Moore mentioned Caroline Dowell's findings of 100 employed women, 35 of whom had not lost wages due to their incontinence. They would take Rostered Days Off, Time in Lieu and use lunch breaks to attend to their incontinence needs. They accommodated their disability within the work environment. Irenie pointed out that the hourly wage could still be used as a proxy for lost productivity.

Terri Jackson posed four questions. Firstly; is the management of incontinence inappropriate? Are we using more resources to manage patients inappropriately? Could it be more cost effective (patients not treated versus patients being treated inappropriately)? Secondly, costs of nursing home admission of clients with incontinence are obviously a major problem, a headline policy issue. Thirdly, the inequitable way in which patient costs are distributed (pads and appliances); is this a major problem across states versus Commonwealth? Lastly, technology needs to be considered, e.g. the previous MSAC review of electrostimulation therapy raised questions in this area.

Kate Moore added that only 30 per cent of patients come forward with their symptoms. Helen Lapsley asked, "is there a percentage of patients who could be cured if they came forward?" and suggested that most would believe their condition was untreatable and that nothing could be done. Incontinence prevention was offered but its value was unknown. The definition of incontinence was "objectively demonstrated leakage of urine from the urethra that is a social or hygienic problem", but no one has defined who should "perceive" the problem e.g. the husband bothered by coital leakage or the daughter acting as carer for her foul-smelling mother. Kate also commented that there were few good longitudinal studies and that a "Do Nothing Approach" had not been measured. Moller et al. (2000) had performed a short longitudinal study showing that incontinence does wax and wane over time. This agreed with Samuelson et al. (2000) who showed that in a group of 382 Swedish women aged 20-59, the annual spontaneous remission rate of incontinence was 27.8 per cent over 5 years (or 6 per cent per annum). Don Wilson in NZ conducted an RCT of postnatal patients, half of whom were given a regime of pelvic floor exercises versus a "do nothing" leaflet, and seen at 6 and 16 weeks. Of 750 patients, there was a significant decrease in incontinence in the active group, but no cost data were provided.

Returning again to the Literature Review, Ian noted that conventional billing data was featured by the US studies. Most studies compared two treatments, with rather poor cost methods, and no intangible costs were collected.

The NATSEM paper (re diabetes) and the Scott Ramsay study used interesting models. The comparison with diabetes was unfair because you cannot cure diabetes, you can only manage it, and there will always be a cost. On the other hand, you can cure a large percentage of incontinence. Helen Lapsley asked the question "how long is the stay in a health care setting and does the patient or relative wait for recovery?" Helen noted that because incontinence has acute and chronic phases, with so many different settings, it "has everything for the economist!!"

Recent data showed that the quicker you get your total hip replacement, the better you will do, because the longer you wait the worse your hip will get. Such information is not known for incontinence (as of October 2001).

Kate Moore suggested we need to recommend to the Minister that a longitudinal study should take place and that Minister should recommend that funding be set-aside for this. Helen Lapsley seconded this idea strongly.

Terri Jackson noted that the Newcastle Longitudinal Project of Women's Health could answer this question. Kate explained that Wendy Brown received $80,000 for a follow up study of those in the first "cut" who had incontinence, particularly those who were lost to follow up, to be chased up and find out how their incontinence progressed over time. The group recommended that this longitudinal study, and the incontinence subset of it, needs to be pursued. The data from it will be important to Project 3, in terms of natural history and consideration of "No Treatment" outcomes.

Terri Jackson suggested we might set up an Australian model based on the Ramsay model (which uses AHCPR guidelines), and include Australian incidence data. There are gaps in the data that would be needed but once these were identified, funding could be allocated for this. Clinicians to peruse and validate the plausibility of the estimates used in the model, and if sufficient data are available, the accuracy of the findings. To construct a Ramsay model would take several weeks, presuming there was enough data to "populate" the model.

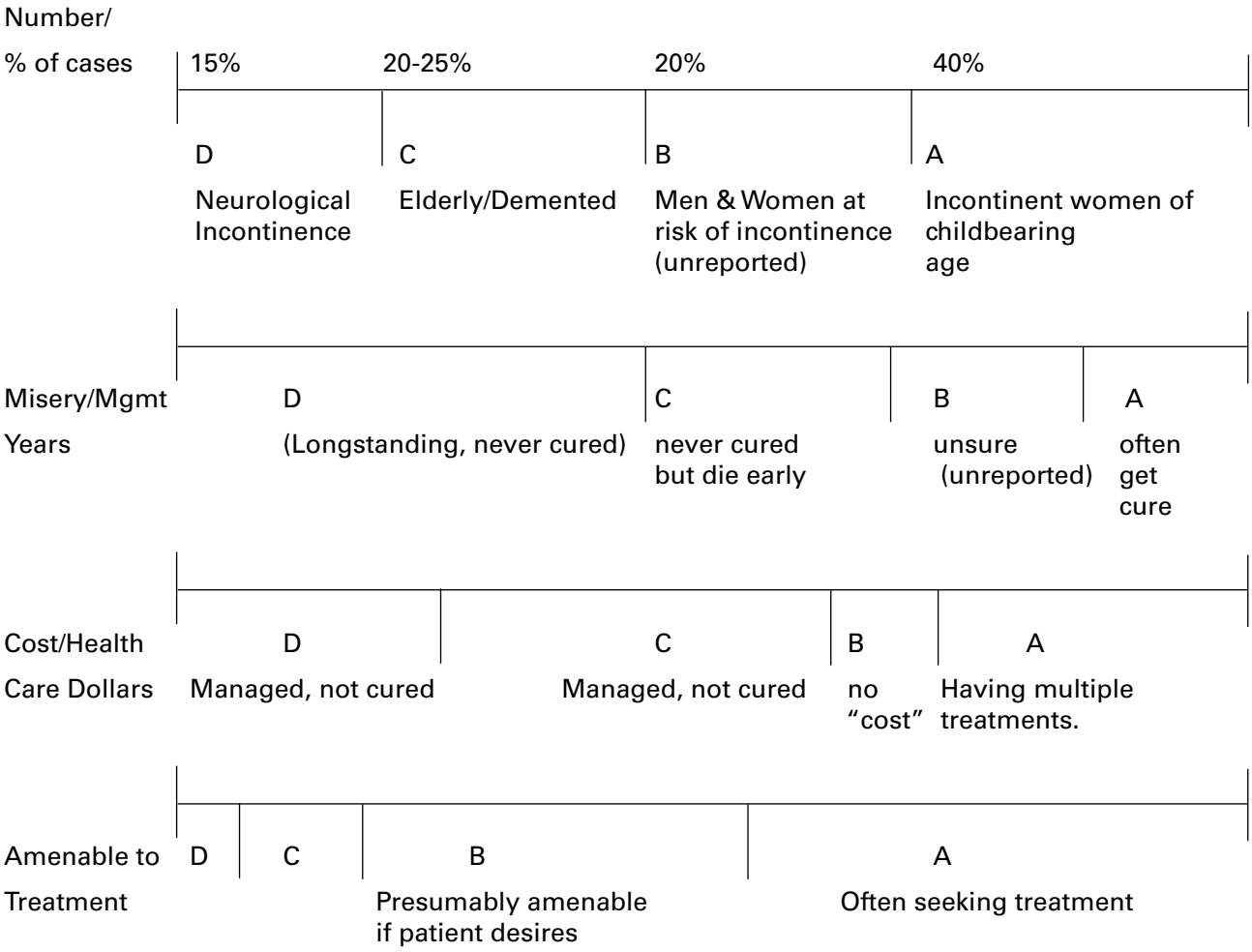
Helen Lapsley pointed out to the group that there was no strategy for prevention. Kate Moore commented that there was no data or evidence that prevention was cost effective, even despite Pauline Chiarelli's thesis on this subject. Both Kate and Helen commented that prevention and compliance were both issues to be considered.

The Wendy Brown data could perhaps obtain matched data about people who had no treatment versus active treatment, but then it would not be known if they were cured. The group felt it would be useful to "scope" the Ramsay model in the Australian environment to see how much data gaps would exist, use the AHCPR guidelines, and see if the model could be "populated". This would have to be part of Project 3. The AHCPR guidelines should also be validated in the Australian context – are they meaningful here?

It was noted in the Gunthorpe paper, that GP's had used a screening questionnaire and showed that simple, early intervention produced a 74 per cent reduction in leakage on 24 hour pad test (n = 82), but there was no cost data in this paper. Retrospective costing of this study might be possible. The GPs were given simple training sessions. There were no comparison groups however.

Terri Jackson then suggested that we needed to step back and look at the 4 sub-groups and 3 settings of incontinence to consider the "burdens of disease". Two separate matrixes were considered regarding the burden of disease. Terri Jackson asked Kate Moore to estimate roughly the percentages of the sub-groups and their levels of incontinence. The following diagram was drawn:

Table 57 Burden of Disease Diagram



Within the bottom line, regarding treatment, Terri pointed out that if treatable patients are given inappropriate therapy this will cost *more* than correct treatment.

D (Chronic intractable) = 15 per cent: never goes away and patients live a long time. Incontinence associated with neurological disease (virtually no publications on costs or natural history of disease).

C (Nursing home patients) = 50 per cent: incontinent but account for only 5 per cent of all elderly patients, but will probably die quickly (not many years of incontinence) and elderly/demented patients who are not necessarily in nursing homes. Many of these are incontinent and lifespan is unknown.

A (After childbirth) = 30 per cent: are incontinent, but a lot of spontaneous resolution after stopping breastfeeding occurs. If they remain obese, constipated etc. and seek no treatment, they may remain incontinent.

B (People at risk): or those who may leak some urine but perceive no social or hygienic problem, of whom we do not know how many are treatable or curable.

The group returned to Section 3 of the First Report re proposed pilots. Kate Moore suggested Project 3 (field trials) should involve the collection of a sample of national data. Terri Jackson added that this should include all groups, all admissions using ICD code, rather than just DRG's. The DRG's do not always make sense for incontinence. A discussion took place regarding coders and their need for specific codes. Ian Brown asked whether this could be funded and how manageable would it be. Terri Jackson suggested that we narrow down to "core" incontinence codes that, say, 20 per cent outside the core definitions are likely to either misestimate (because codes are too vague), but the use of DRGs increases variations. Tessa Ho added that specific procedural codes are also going to be relevant, stick to the ICD Code.

The group concluded that an epidemiology study of the "misery burden" or "burden of disease" (Mathers et al. 2001) across these groups is needed before we can move to dollars. Who would score the worst on Activities of Daily Living; probably group D (as described in Section 6 of the First Report regarding people with intractable incontinence) who account for 15 per cent of the total with the disease but maybe 50 per cent of the misery. People in nursing homes (group C) may have the next greatest burden of disease, but may be too demented to know about it. Also group A (childbearing age) are having a lot of operations for incontinence. In group D (neurological disease) their incontinence costs are "marginal" because they cost a lot for their neurological disease, per se, and the incontinence costs are just the "icing on the cake," so to speak.

Then the group examined who are treatable. The elderly non-demented often do not get much treatment, but more is available than what is given out presently.

The group then discussed the concept of the "DALY", defined as Disability-adjusted life year which is a measure of health gain in economic evaluation in which the quality of life gained is adjusted for the effects of the illness on disability. DALY is used in two ways: first, to calculate the global burden of disease by estimating the extent to which disease causes loss of life and disability in a geographically defined population; and second, as a generic measure for use in cost-effectiveness analyses. The measure combines an estimate of the duration of time lost due to premature death. This measure represents a social value of time lived at different ages plus a weight of disability and a discount rate. The social value of time is calculated to reflect the different social roles of different age groups and the dependence of some age groups on others e.g. different weights are attached to those who are carers of young children or the elderly. Disability is weighted according to a table which sets out various weights for classes of disability states.

Professor Moore stated that surgery is not the first line of management of incontinence according to AHCPR guidelines. Surgery should only be offered to those with documented failure of conservative therapy. Could the field trials in Project 3 look at Conservative Treatment versus Surgery? It is known that 60 per cent of mild and 35 per cent of moderate incontinence [Moore, et al. 2003] will be cured with conservative therapy and won't need surgery. Comment should be made on the variable surgery rate for incontinence and discuss the cost impacts. The potential for inappropriate treatment is large. Only one RCT of conservative therapy versus surgery is in the literature but no cost data was provided, and unfortunately they didn't control for severity, a very old paper.

From the First Report Section 3.1.2. – Patients admitted for treatment of conditions associated with incontinence (falls, urinary tract infection, skin breakdowns). Incontinence is a Secondary Diagnosis: Second diagnosis leads to coding and patient attention given by NCAs on admission to hospital. We need to check whether incontinence is routinely coded by coders who see the green NCA sticker. It is not known whether there are clear guidelines as to when to call the NCAs. Relatives may refuse to take the patients home due to their incontinence. The NCA is called to sort them out and this often prolongs the length of stay.

A snapshot census of incontinence in St. George Hospital has been suggested. We have ethics approval for this project. Helen Lapsley mentioned her study of discharge adequacy at St. Vincent's Hospital,

where she found about 80 patients of 480 beds, who should have been sent home. Helen Lapsley suggested a one-night hospital census of all wards. We could use two male and female wards, for a pilot study. To check veracity of the census by the coding, wait until patients go home. This will need separate funding. It would be noted if patients were being held on the ward because of incontinence. The group resolved to take the census, but not to check the coding for those in the census, until Project 3.

The group discussed Item 3.1.4, the cost of non-admitted services (outpatient and emergency department services) at public and private hospital. Regarding Anderson and Louey, 1999, paper on suprapubic catheter clinics, one method of retrospective cost collection could be through "admissions triage ". Ian Brown suggested retrospective costs of could be ascertained by "triage code" from South Australian Health or Victorian Health, to get the cost of the old-style visits to casualty for suprapubic catheter changes. With outpatients, they could log their time for the next 50 patients referred to them. Terri Jackson suggested we might be able to glean data from the Ambulance Service data system to lead to patients with emergency admissions for urinary problems. We could get cost of admitting patients to day-surgery in the old-style then compare the costs once the SPC (suprapubic Catheter) changes were done in the Pelvic Floor Unit. The group discussed the fact that service was increased by one NCA; the cost was $40,000 per annum, versus hundreds of casualty and day-only admissions. The economists had difficulty coming to grips with the enormous efficiency of the new system. Helen Lapsley said this project could be costed retrospectively. Terri Jackson said the NCAs would have to log their activities for a sampling period, including down time and administrative duties. What are all the other Change of SPCs doing in Sydney? We need to document this; we can't assume it is the same as our historical control. Terri suggested that the costing be done, and then one could apply for a grant to liaise with all the ambulance drivers in Sydney to check what other centres do in Sydney. The retrospective costing could be done in Project 2 and the comparative study could be undertaken in the Project 3 field trials.

Section 3.1.5, Patients admitted for Sub-acute and Non-acute Care, when Incontinence is not the Primary Diagnosis (SNAP), was discussed. Case types have been corrected for geriatric evaluation and management (GEM= 4, Maintenance = 5.) The retrospective analysis of data will be completed by the Centre for Health Service Development, University of Wollongong. Janette Green together with Rob Gordon will do the analysis. They will also look at the 18 item Functional Independence Measure (FIM) for bladder management and bowel management. Analysis may include splitting them into types of management, looking at the cost for patients with and without incontinence and with bladder only or both and looking at costs per episode of care. Greg Perry, current FIM co-ordinator, NSW Health (Master Trainer), suggested that exact matching could be problematic and that we should designate 1- 4 as continent for bladder management because if a patient is immobile and someone has to bring them a bed pan, they will be scored as a 5 although they are not necessarily incontinent. Simple regression analysis was discussed, yes or no for incontinence versus using a more complete model instead of trying to match patients on characteristics. A teleconference is to be arranged, as the group felt this would be more manageable.

Section 3.2 The Cost and the utilisation of residential care services attributable to incontinence was discussed regarding two pilot studies being conducted in nursing homes with 300-360 beds each, co-located to hostels with low and high dependency areas. Consecutive patients to be flagged and this is already underway by Dr Peter Gonski. A data analysis nursing chart has been compiled regarding costs of care, toileting time, pad changes, types of pads colour coded, bed changes. All pads are to be supplied by Hartman's Company who do a three-day base-line study, weigh the pads, get the correct type of pad, and allocate the correct type to each patient. The cost to the company is reduced when they undertake this precise strategy. They keep notes for the patients that they monitor.

So, Dr Gonski has two sites, one for elderly neurological patients in the ward, and another acute inpatient ward for dementia patients. Ian Brown asked whether domiciliary nurses had the same level of sophistication regarding continence management. The RNs in South Australia had focused on the costs of continence management for home-based care. Helen mentioned that the nursing services had instituted seven-day per week care, because people used to be admitted due to home nursing only being available for five days. Dr Gonski must know about this, i.e. the continence aspects of home nursing services.

The ACAT team commented that assessment is inconsistent; is the patient "continent", "incontinent" or "not known ". But the existence of home nursing services should be explored. Ian Brown explained that DVA are knowledgeable about this. DVA hold all the relevant data sets. Home Care is generally funded through HACC (Commonwealth and State shared funding 40: 60). This issue needs to be explored.

Who is bearing the costs? There are perverse incentives; families try to get their elderly into nursing homes partly to disperse their costs, especially for poorer families who receive inadequate community

support of costs. Does the National Hospital Cost Data Collection have public and private hospitals in it? Is the incidence of continence procedures more common in the privately insured compared to the public patient? What about Gap payments? This small area of variation would need to be considered in the Project 3 field trial. Gap payments impact upon personal cost.

Kate Moore mentioned intangible costs of incontinence. The Project 1 Group need to describe what quality of life measures they are going to recommend. Once decided the impact it has upon the indirect/ intangible cost needs to be considered. Kate Moore mentioned the IIQ and the UDI but they don't describe time off work. Helen suspected that carers withdrawing from the workforce are not being documented.

Terri Jackson was not sure what to do about measuring intangibles, as current measures are relatively insensitive to the dimensions of importance in incontinence. She also mentioned the problems with cost-benefit analysis in assigning dollar value to misery, and whether this has meaning in comparative analysis studies: you should measure the change in quality of life, and then try to put dollars to it – this could entail some heroic assumptions. New techniques = Contingent Valuation and Conjoint Analysis are becoming more widely used (Helen teaches this to undergraduates). They ask patients a series of questions about dollar values and treatment outcome tradeoffs they would be prepared to make. It gives a value to freedom from incontinence, and moves away from the problem that what you're willing to pay for a treatment is directly related to how much money you have (the low income problem). It is not used much in Australia yet but it could be pursued. Helen is aware of the emerging literature. Both were wary as the technique is something of a "black box".

Summary

What to do next? The problem of the lack of outcome measures remains. The discussion has been very valuable. The pilot projects will be discussed this afternoon, and criticised by other incontinence workers. Most importantly there will be Alison Brookes from Project 1, who will be asked to give a thumbnail sketch of their progress.

Morning session closed at 12.30pm, the meeting resumed at 1.30pm. Afternoon Session: Meeting of Stakeholders, Health Economists & Complete Project Team

Present:

Project Team: A/Prof Kate Moore, Dr Helen Lapsley, Dr Tessa Ho, Mr Ian Brown, Ms Irenie Smoker, Dr Chris Poulos (via teleconference), Ms Caroline Dowell, Dr Peter Gonski, Dr Alastair Morris, Joan Walsh, Marilyn Gibson Jones, Lee Wells, Jan Swinfield, Mr Derek Huckel, Angela Ingram.

Stakeholders: Dr Terri Jackson, Ms Jan Sansoni, Dr Alison Brooks, Dr Michael Wishaw, Cheryl Mead, Angela Crocket, Ellen O'Connell, Rhonda Brownlow, Virginia Ip, Charmaine Bryant, Denise Edgar

Kate Moore expressed that the need for an update from the Outcomes Project was highlighted in the morning's discussion with the health economists, who repeatedly stressed that outcomes were essential to determining the value of the money spent upon incontinence treatment or management. The money spent needs to provide "cure", or reduce the burden of disease. Helen Lapsley indicated that the study of the framework for economic analysis cannot be completed until we are informed by some outcome measures.

Alison Brookes indicated that Project 1 commenced 6-8 weeks after Project 2, but the retrieval of literature is still in progress. They are looking at a variety of outcome measures for different care settings and client groups, including clinical efficacy and quality of life. The team has requested over 600 references and expect to examine closely about 10 per cent of those. Helen Lapsley asked when precisely we might have a draft of the outcomes document. The response was early January 2002 for a first report, followed by the review of expert panels to give rise to a subsequent final report.

Jan Sansoni mentioned that the Outcomes Project will look at quality of life and clinical outcomes, but Project 2 might be able to look at any Utility Index or Burden of Disease data that might be available. Helen Lapsley indicated that the literature is rather bare regarding the use of Utility Indexes i.e. only one paper was encountered. Helen pointed out that we have covered all the literature to date in the various client categories but much of the literature comprised very basic "cost of illness data". This morning we have discussed what kinds of studies will be needed in Project 3, and we examined the pilot projects that are in progress. We kept concluding that we really must have information about outcomes before we can go further in recommending future studies.

The group turned to the First Report. The literature review was rather fragmentary and very American. Some definition problems were encountered. Tessa Ho outlined the Pilot Study being conducted by Chris Poulos and his staff at Port Kembla Hospital. This is taking place in two wards; one which is predominantly rehabilitation and the other which contain patients with neurological problems, rehabilitation, brain injury, stroke and also geriatric syndromes and dementia. Tessa also described the design of a bed chart used in this study. The sheet was located at the end of the bed and recorded staff time, toileting and washing of patients, pad usage and quantity, medications and diagnostic needs.

Joan Walsh (Sutherland Hospital) has designed a newer form (the "Blue Sheet") following a meeting with Chris Poulos and Dr Ray O'Sullivan (see Appendix D). Joan Walsh has prepared an information kit for use by her staff (see Appendix C) outlining the reasons for the study, the methods of collecting data etc. Both hospitals, Port Kembla and Sutherland will be using this.

Kate Moore reiterated that we are trying to capture the costs of incontinence for 20 consecutive patients; we need to establish common forms for the Gonski and Poulos sites. Joan Walsh explained that you might wash the patient and then change the linen and change all the clothes and put in a fresh Kylie sheet, but you could not code all these activities in one box, so the form was modified. Tessa then explained that she had asked about the cost of laundering the patients' clothes. She found if they were hospital pyjamas, the hospital would launder them. However, if they were "private" pyjamas, but the patient had no family to launder them, then the nurses would actually wash them out and put them to dry, out of the goodness of their heart so to speak. In one ward there is a washing machine, but the nurses may have to pitch in.

Dr Michael Wishaw, from Melbourne, asked about patients who were not wet but had a bladder control problem. Joan Walsh pointed out that time needs to be recorded for performing an assessment if they need extra toileting. Chris Poulos pointed out how long is a piece of string; if you keep patients in bed without toileting for long enough, they will all become incontinent, where do you draw the line? He also questioned whether we should use clinical scenarios to check that all individuals complete the form identically. Joan Walsh explained the in-service teaching that she had devised to maintain consistency across all staff recordings.

Peter Gonski posed the question "what is incontinence?". The group discussed terminology. Peter Gonski responded "two or more incontinent episodes over two days" as the minimum occurrence to be classed as "incontinent ". Alison Brooks agreed that there really was no clear consensus on what "incontinent" meant. Professor Moore replied that in gynaecology, the patient tells me she is incontinent because she doesn't like the smell or because she is buying incontinence pads, but in a geriatric ward, we need a more specific definition. Dr Gonski felt two accidents within two days was appropriate. Dr. Poulos asked whether a reasonable patient would become incontinent if left too long in the bed, you need a reasonable number of instances to classify it in the ward setting. The group agreed that Peter Gonski's measure of 2 incontinent episodes over 2 consecutive days = incontinent. The nursing staff needs to label a patient incontinent as one who can't reach the toilet.

The group then returned to the discussion regarding the definition of incontinence and people with a catheter, who don't leak but depend on resources. Peter Gonski suggested we focus on "incontinence" not "types of bladder complaints ". Regarding faecal incontinence, Peter Gonski and the group discussed faecal overflow as a legitimate incontinent episode but that the group should exclude faecal overflow as a result of medical treatments, laxatives, enemas etc. Faecal incontinence should be measured as for urinary i.e. 1 per day over 2 consecutive days. Chris Poulos mentioned that pure dementia-related incontinence should also be included. Kate Moore pointed out that dementia patients formed a large part of the study group. Peter Gonski responded that dementia, as a cause, is not being recorded to date in the pilot studies. The type of incontinence should be noted on the back of the blue form, but a formal definition of the type of aetiology is too difficult for this project. Once the patient is defined as incontinent, that should be sufficient.

Sutherland Hospital/Dr Gonski's Pilot Studies

The group discussed attending a nursing home setting for one week to collect data from 20 patients. Would it be possible to collect data retrospectively on 10 patients and obtain the other 10 in the following fortnight? Peter Gonski wondered whether a more realistic timeframe was two months as some patients are admitted continent and later become incontinent. Also, was the data collected to capture the level of incontinence per patient, or, the management costs of the incontinent patient as a whole? Ian Brown questioned whether we were measuring the cost of incontinence or the cost of management. Helen Lapsley and Irenie Smoker added that assistance time for each patient increased labour costs and so did intervention. Cheryl Meade pointed out that if they are on a timed toileting

regime and no longer incontinent, then they are costing money to manage and should be included, if they were incontinent upon admission. This is especially because patients' pads are being managed by Molycare management programme, so they may have been rendered continent by the management system. This system may use more pads, and not all nursing homes use this system. Terry Jackson pointed out that because not all institutions use this system, we were comparing apples with oranges. Terry then suggested we document the apples and oranges, e.g. who is and is not using the system. Jan Swinfield pointed out that at night, nurses might run out of pads and grab the largest one available to keep patients dry overnight, due to short staffing. So that is the real cost and we need to capture these costs. If they are not actually wet, do not include them. Irene disagreed; if they were incontinent on admission and need this cost of management we should include it. Helen Lapsley then concluded we should stick to those who are actually now incontinent, but should tell those undertaking field trials (Project 3) that they should include those patients who are continent because of their management strategy.

Hostels

Jan Swinfield will be collecting data from hostels. There are two categories within the hostel setting; high-level care and lower level care. It was noted that hostels receive extra funding for high level dependent patients. Kate Moore asked if there was a handbook on the assessment of level of care required within hostels i.e. PCA, RN, AIN, and EN etc. Kate also posed the question of how to track patients in the hostel setting and if one week would be enough time to do so. Caroline Dowell suggested using the DBICI: she and Jan Swinfield could spend time on this. Ian Brown asked if all care costs in hostels would be noted and Caroline Dowell responded that all costs i.e. GP, surgery etc are all noted on the DBICI form.

"High Level Care"

The definition of a high level 2624 category was discussed. In the hostel, personal care attendants (PCAs) are the main workers. The hostel might only have 6 hours per week of Registered Nurse care. The person who needs nursing help at night would be cared for by a PCA. Ian Brown suggested including high level 2624 patients in the hostel, but Peter Gonski felt these must not be included in Project 2. Helen Lapsley noted these patients have not been picked up before. P Gonski said it is very complex re small villages and large hostels. So the consensus was that no high level 2624 patients were to be included in the pilot project of the hostels, only those who buy their own pads or are on DVA/PADP to be included.

Next question: what data to collect on these self-caring patients over one week, who are going out playing bowls? Tessa suggested performing the DBICI on them for one week. This could be a lot of work. Hostel patients may also be getting community nursing care. Could the DBICI be converted to a checklist at the end of the bed? Caroline Dowell explained that patients cannot fill in the DBICI themselves. Caroline explained that the DBICI could easily be administered to hostel patients. Jan asked whether care costs for hostel patients can be obtained from another source. Caroline said no, GP visits etc are not recorded in hostels. The group broke for afternoon tea.

Retrospective Analysis of FIM Scores of the SNAP Data Set:

The FIM scores were discussed, for SNAP classification respective analysis. Irenie Smoker stated that the FIM contains two items relevant to incontinence; one for bladder and one for bowel management. Kate Moore indicated that a retrospective analysis of episodes of patients with and without incontinence will be undertaken. Irenie explained that the definition of "incontinence" was not clear. There are seven classes for each of 18 items. For the items of bladder and bowel management, a person who manages themselves independently but is still incontinent may not be classed as incontinent on a FIM score. Angela Crockett from Aged Care explained there are problems with lack of training on how to perform FIM scores and also that the assessment of continence is very subjective. If a patient needs grab rails or help getting to the toilet, they are not totally independent. Irenie explained on a scale of 1- 7, that 1- 4 represented incontinent, 5= needed pan or urinal. 1= total dependency and 7= independent. Caroline Dowell stated that her ACAT team was no longer using FIM scores because they are too complicated. Kate Moore suggested multiple statistical assessment, 1 versus 2- 6, and 1-4 versus 4-7. P Gonski asked whether you want to record the FIM scores we are currently using. Answer: yes please, record it on the back of the blue form. Michael Wishaw explained he does not use FIM as the Barthel Index is used at his facility.

Community Care Setting:

Caroline Dowell described Home Care visits versus Clinic Consultations. Patients seen by Caroline Dowell should be seen at the clinic if able, but she does not have a means of proof of the patient's

inability to attend the clinic. Therefore, if asked for, a home visit is granted. Kate Moore thought that home visit clients would be sicker than clinic visit clients. This is not really true. Rhonda Brownlow (Peakhurst Community Health Centre) said, if the patient is able to get to their GP, then they can see her in the clinic. However, Caroline's clinic is poorly accessible with little parking or elevator access. Rhonda Brownlow, Denise Edgar, Angela Crocket and Ellen O'Connell all visit clients at home; they do not possess a clinic facility. All agreed that aged care assessment in the home gives greater information than "out of home" assessments. Angela Crocket pointed out that sometimes only a home visit is applicable to patients who are home bound. The group agreed that this needs to be written up and documented. Michael Wishaw agreed that the home visit was much more informative. Denise Edgar pointed out that she is HACC funded and cannot make home visits as there are no travel funds. Caroline explained the need to see whether they require a handrail to get to the toilet, making it essential to actually visit the home. Michael Wishaw pointed out that the Incontinence Assessment is often the gateway to the Geriatric Service; it can act as the entry point.

Kate asked if anyone had looked at the efficacy of home visits versus clinic visits. Dr Gonski explained that home visits have been clearly established to be more effective than clinic visits, for all aged care services generally. Angela Crocket explained how she saw a patient due to have surgery who asked for a home visit because she was terrified of being incontinent in hospital. She had no mobility at all; a clinic visit would have been impossible. Kate concluded that one needed to include this issue of home visits in the final report.

Kate Moore asked for information on Home Care services and private nursing services, a paragraph needs to be written on this. Caroline Dowell mentioned that Home Care sees to client needs and also services. The HAC Liaison Officer for St. George and Sutherland area (Marie) can provide information re criteria for various services. A few of the service groups were mentioned; Regal Aide, Nurses on Wheels, Loretta, Dial an Angel and also private agencies. Community Options (COP) is a funded organisation. Department of Veterans' Affairs also provides home visits. HACC services liaison officers should be able to provide information on all such services. Many private nursing services are refunded by some health funds. The Final Report should include an overview of this subject. Insurance companies also provide private nursing care to road trauma victims. It was suggested that Project 3 would address these costs and define them more clearly.

Home Care can only offer 14 hours nursing time per week, so "top ups" may be provided by COP. Michael Wishaw explained that a lot of elderly people would receive hygiene care privately. Multiple Sclerosis patients often need a lot more nursing care for toileting than is available from public services. A thumbnail sketch of this source of incontinence expenditure is needed. Peter Gonski explained that every area uses different services. Kate Moore explained that complete listing is not needed for Project 2 but may well be needed for proposed field trials in Project 3.

Helen Lapsley suggested that at a later date a project could be undertaken to assess the costs borne in the home and agencies relating to care of incontinent patients at home.

The DBICI in the Acute Hospital and Outpatients Clinics:

The DBICI was then discussed. Caroline Dowell talked about the DBICI – what do patients use? (pads/ tissues etc.) Alastair Morris felt that the DBICI was a little time consuming. He showed patients a list of pads and asked which ones they used and they usually recall. Caroline pointed out that they need prompting about changes of underwear, tissue in the pants etc. Tessa asked whether a male interviewer could affect the answers. In his experience in the Pelvic Floor Unit of St. George Hospital Alastair felt it was not always appropriate to note types of drugs taken e.g. anticholinergics. Is the HRT really used "for incontinence?". Not all patients are aware of what type of medication they are taking, especially over the last 12 months, nor the reason for taking it. Charmaine Bryant felt that most patients were fairly in tune with their costs etc. but did require detailed questioning. Mike Wishaw found patients often did know what or why they were on medication and like Alastair's experience, why an IVP should be performed "for incontinence?" But if patients pay a gap for GP visits, patients often remember it, also if they pay a "gap" for urodynamics. The purpose of this DBICI endeavour is to get a picture of all types of incontinence costs.

Kate Moore suggested that St. George was the primary hospital for incontinence cost studies, however, there were few urology outpatient clinics to study in New South Wales. Charmaine Bryant pointed out that RNS Hospital has a male urology clinic but only for previous inpatients. The Pelvic Floor Unit sees 4,000 patients per year and intakes 600 new patients per year. This database is kept by Jan Swinfield but has not been utilised to date, as it has no funding from NSW Health. Kate queried if this data could be used in Project 3. The 20 consecutive patients that Alastair Morris is giving the DBICI to should

inform Project 3, regards another opportunity to collect data. Kate Moore said that in the Pelvic Floor Unit, we do ascertain "cure" (=90 per cent dry), "partial response" (=50-90 per cent), "failure" (< 50 per cent response), and patients who do not attend, a letter is sent to their GPs advising of this, together with a summary of their current response level. The long range aim of the database is to establish cost per cure, but no funding is available for this database.

Hospital Setting: St. George Outpatients and Inpatients

Virginia Ip (Nurse Continence Adviser) sees males as outpatients due to post prostatectomy incontinence. This should be noted for the proposed field trials in Project 3. In the wards, neurological, frail/elderly, childbearing age, patients x 30 are being tracked, although there is no specialised data collection per se. There are difficulties in collecting data, as the staff do not have time due to workload. Family members are asked and not a lot of information is kept in the hospital notes. The ward sister rings the NCA to ask for a visit to an incontinent patient. This is a different facet of the demand for hospital services for incontinence. A criteria needs to be formulated for NCA use. The question asked is "does incontinence increase the length of patient stay in hospital?"

Kate Moore: Does continence relate to the patient's admission? We are performing a retrospective analysis of IDC codes for incontinence over one month, forward and backwards in time. A snapshot of each patient on admission, questioning patients re incontinence, is also under consideration, eg a census. Helen thought we might not have enough resources to complete the census as part of Project 2. Michael Wishaw suggested that we should seek 20 consecutive incontinent patients at St. George Hospital however, because this could range from bunionectomy patients to neurosurgery cases, a small sample would be biased.

Peter Gonski: Other wards which do have some aged care patients, staff could be asked at hand over if any of their patients have continence issues? Helen pointed out that even if this was done, those patients might not be costing anything for their incontinence, and so what would it mean economically? Joan Walsh said other ward staff at Sutherland could also be asked at hand over. Peter Gonski was also positive about taking a census via the nursing staff at hand over at Sutherland; it would not be an enormous task. Michael Wishaw pointed out this would not threaten the patients; it would be via the nursing staff. Tessa Ho agreed that we could put some funding into this project. This is an action task for consideration.

Helen Lapsley stressed that early intervention was a key question and to what extent should we intervene and to whom. Measures of effectiveness are essential to economic analysis. Is there an economic benefit to early intervention – must have data. Issues such as direct costs, the ability or inability to work, the loss of employment, the question of productivity, compensation and early retirement by an adult offspring to care for someone with incontinence need to be addressed. Helen also listed these issues: Pensions, inequity issues – who pays for their own pads and who doesn't, who is at home, buying their own pads, versus living in institutions, which institutions provide and don't provide pads.

Michael Wishaw stated that these points vary from State to State. The group discussed the incidence of time lost from work due to incontinence. Helen Lapsley, Alastair Morris and Tessa Ho reiterated that the patients transfer work time to rostered days off and leave to see to their personal matters re incontinence. Caroline had met teachers who had to give up their jobs because they couldn't last through the class. Faecal incontinence is also likely to cause loss of employment, or lower grade employment. Loss of work time versus time off in lieu needs to be discussed especially in Project 3 (field trials).

Michael Wishaw asked the question: Does DBICI cover people who have altered their work or type of work due to incontinence? Could we study this in the outpatient client group? What about carers who give up work?

Rhonda Brownlow outlined the possible occupational problems e.g. schoolteachers having to remain in classrooms for lengthy periods of time and may just wet themselves in the class etc. Alastair Morris made mention of patients in these types of occupations etc. who would like to take advantage of treatments available would rather use alternate methods of treatment (eg rather than use the Neotonus Electromagnetic chair) because of time factors involved. Kate explained that this issue has just not been dealt with in the literature to date. Ian Brown concurred with this. Irenie Smoker felt that Pilot studies were very useful. To cost these factors could be undertaken further down the track. The questions we are faced with are; 1. What needs to be done to prevent incontinence? 2. Do we want to look at cost prevention? 3. Who bears the cost? Kate Moore pointed out that to date we are mostly collecting "cost of illness" data. However, if we apply a treatment that costs money, we need to know if that money is well spent. We need to know if after two treatments, is one better than the other. We do not know what "NO" treatment is. We also have no answer to "what is treatment?" Kate mentioned the Gunnar Lose

paper about the variability of incontinence symptoms over time. We need to know the natural history, and costs to the patient, of "No treatment ". Kate Moore indicated surveying of the DRG re incontinence and checking the accuracy of the coders is underway. Kate mentioned the issue of conducting pilots of women of childbearing age, which is included in the project. The whole issue of incontinence prevention has not really been tackled yet in Project 2.

Tessa Ho reiterated the 6 key groups and in particular "Men and Women at Risk" and asked for a definition of "at risk ". The definition of "prevention" versus "early detection" remains unclear. How does one decide when prevention versus screening versus early treatment is taking place? Kate Moore suggested the screening of patients to determine prevention or detection at an entry to hospital level as the best means of obtaining this. Denise Edgar agreed that we have no data about the value of incontinence prevention. To be highlighted for consideration by the Project 3 field trials.

All members were thanked for their attendance and time.

The meeting closed at 4.45pm

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